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Ordinary lives

Disabled children and their families

A guide for donors and funders



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A guide for donors and funders

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Executive summary

The need

There are an estimated 700,000 disabled children in the UK (5% of all children). Disabled children have the same needs as other children: to learn, have fun, make friends, play and go on holiday. However, they face many barriers that prevent them from doing these things, leading to loneliness and frustration. Many disabled children do not get the equipment, therapy or communication aids they require. This can slow their development and limit their capacity to take part in everyday activities.

Almost all disabled children live at home where they are valued and loved. Unfortunately, their families are more likely to live in poverty and have high levels of debt. This is because the cost of raising a disabled child is three times greater than for a non-disabled child, and parents are often unable to work because of intense care requirements. Most families do not receive any breaks from this care. Furthermore, nearly three quarters of families with a disabled child live in unsuitable housing. In addition to the practical difficulties, families often experience emotional devastation, anxiety and loneliness.

Role of the public sector

The government plays the primary role in providing financial support and services for disabled children and their families. However, benefits and services have too many exclusionary criteria attached and are not reaching enough families. Recently, central government has shown an increased commitment to supporting disabled children. Given the lack of funding and the increasing degree of local autonomy, this is not translating to local provision. The government should expand the benefits system and ensure local implementation of the various acts and initiatives it has trumpeted.

Role of the charitable sector

Given the government's responsibility, the role of charities might appear less obvious; however, it is no less important. Charities are often the first port of call for families. They provide emotional support, information and help in navigating and accessing the range of available services and benefits. As providers of services such as short breaks, and leisure and arts projects, charities often use voluntary donations to experiment with new approaches, which are then rolled out with statutory funding. Charities also inform service providers around the country about changes to legislation, new approaches and activities. Most importantly, they lobby the government and support disabled children and their families to lobby for themselves.

Recommendations for donors and funders

NPC has found a broad range of charities that are carrying out these roles effectively. Donors and funders can support such charities, and be instrumental in improving the quality of life for disabled children and their families. NPC recommends funding a range of charities – from those that support children and families directly, to strategic, national organisations that influence policy and society.

Funders interested in supporting work with disabled children and their families are encouraged to contact NPC for detailed reports on a wide range of exciting opportunities.

Disabled children and their families are often condemned to a life of poverty, loneliness and sub-standard services.

Born Yesterday
Tightly-folded bud,
I have wished you something
None of the others would:
Not the usual stuff
About being beautiful,
Or running off a spring
Of innocence and love –
They will all wish you that,
And should it prove possible,
Well, you're a lucky girl.

But if it shouldn't, then
May you be ordinary;
Have, like other women,
An average of talents:
Not ugly, not good-looking,
Nothing uncustomary
To pull you off your balance,
That, unworkable itself,
Stops all the rest from working.
In fact, may you be dull –
If that is what a skilled,
Vigilant, flexible,
Unemphasised, enthralled
Catching of happiness is called.

Philip Larkin

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Introduction

The purpose of this report

This report is a guide for donors and funders interested in supporting disabled children and their families. It contains the information required to understand the issues and need in this area. It addresses all donors, from private individuals, who may be new to the subject, to grant-makers with extensive experience.

The report focuses on:

- The needs of disabled children and their families.
- Responses and activities by the government and charities.
- The results of these activities.
- Funding priorities.

NPC's research highlights activities that are most likely to benefit disabled children. This allows donors to target resources more efficiently and to maximise impact. NPC can provide detailed reports on specific organisations and assist in grant-making.

Methodology

There were three stages of research for this report: desk research, national fieldwork and local fieldwork.

Desk research

NPC began its research by reviewing relevant legislation and reports. This included government, policy and regulatory documents, and academic papers and research undertaken by some of the larger charities. NPC identified the major players within the sector and approached them for its national fieldwork.

National fieldwork

For its national fieldwork, NPC interviewed 20 individuals from relevant charities, umbrella bodies, central government departments and academia. (For the full list see Acknowledgements.)

The purpose of this was two-fold:

- To establish if, and how, the government and voluntary sector are addressing the needs of disabled children and their families.
- To identify gaps and priority areas for intervention.

Because of the high number of charities in this sector (approximately 300 national groups concerned with specific conditions, and over 1,000 local parent groups)² it was not feasible to visit most of them. NPC selected national charities that work with children with any type of disability and their families and also some of the larger single-condition charities (e.g. Mencap, Scope, and the National Autistic Society).

Local fieldwork

After developing a broad understanding of the sector, NPC conducted two local case studies: in Liverpool and Tower Hamlets. These areas were selected after considering a number of criteria:

- Geography and population demographics.
- Type of local authority, i.e. Metropolitan, London Borough, County or Unitary.
- Comprehensive Performance Assessment (CPA)* and star ratings¹.
- Children's Trust** and Children's Fund** status.

Liverpool and Tower Hamlets are deprived areas and have large black and minority ethnic (BME) communities. Tower Hamlets received a three star (the best) ranking from the Commission for Social Care Inspection (CSCI). At present, it is implementing a Children's Trust aimed at joining up and improving services for all children, specifically disabled children. Liverpool received only a one star rating. It is not one of the Children's Trust pathfinders, but it does have a Children's Fund.

NPC met with local experts, including children's service managers at the local authority and disabled children's team members at the Children's Fund. It also visited numerous charities. The aim was to build a picture of local service provision and identify areas of unmet need.

Scope and content

Because of time limitations and different legal and political frameworks in the various countries of the UK, this report only covers England. However, most of the findings are applicable across the UK and some of the charities cited provide UK-wide services.

The knowledge gained through its local research means NPC is able to quickly identify and evaluate the effectiveness of local charities in other areas.

The age limit for 'children' in this report is 18. However, this is not always useful because different government departments have different age cut-offs. For example, children's health services end at 18 whereas full-time education stops at 16 or 19. Statutory requirements state that planning for the transition between child and adult services should begin when children are age 14. However, this report does not cover the subject of transition because it is a large and arguably distinct research area. NPC plans to cover the issues of transition in a future report.

* The Comprehensive Performance Assessment (CPA) process was introduced for single tier authorities and counties in 2002 and has become the overarching process for central assessment of local authority performance.

¹ Star ratings are issued annually by the Commission for Social Care Inspection (CSCI). They summarise CSCI's independent judgements of performance across all social care services.

** Children's Trusts bring together health, education and social services within a single agency and are designed to enable multi-agency working.

^{††} The Children's Fund is part of the government's agenda to support disadvantaged children and young people, targeting 5–13 year olds (see Appendix 3).

This report examines the emotional, social, physical and financial needs of disabled children and their families. It does not cover specific healthcare interventions or medical research. The issue of Special Educational Needs (SEN) is covered in NPC's report *Making Sense of SEN* (2004); this report only briefly touches on education. Palliative care for children is the subject of NPC's report *Valuing short lives* (2005).

Structure

The report begins by defining disabled children and reviewing the quantitative data on them. The next four sections cover: children, their families, professionals and policy-makers, and society (see Figure 1).

Section 1 considers disabled children themselves. It looks at their needs, and how these needs are, or are not, being met. It examines and lists some of the charities that are addressing the needs of disabled children.

Section 2 considers the families of disabled children. It looks at their needs and the state of provision to meet them. It examines and lists some of the charities that are addressing the needs of these families.

Section 3 looks at how to improve the delivery of services at national and local levels. It sets out the statutory framework for service provision and the degree to which it is implemented. It explores how voluntary donations can have a positive impact on policy and delivery of services.

Section 4 considers what needs to be done to make society more inclusive of disabled children and their families.

Finally, the conclusion summarises the case for private funding and the best way to contribute to this sector. Detailed charity recommendation reports are available from NPC.

NPC's research enables donors to target resources more efficiently to maximise impact.

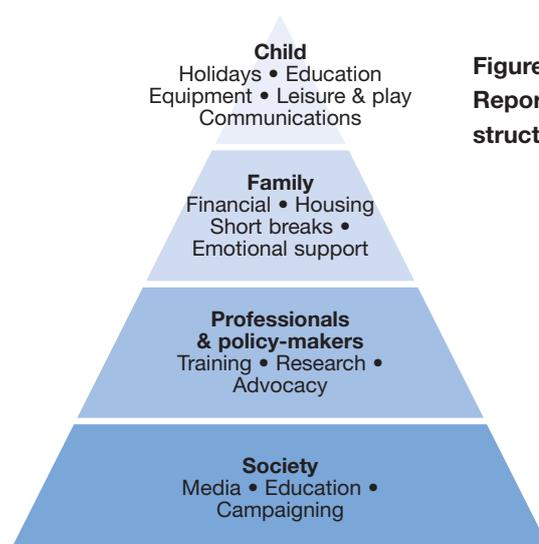


Figure 1:
Report structure

Background

Disability is the interaction between impairment and social, attitudinal, economic or physical barriers.

This section discusses models, definitions and terminology of disability. It presents data on disabled children in the UK, broken down by type of impairment and areas of difficulty. Recent trends in prevalence of disability are discussed, along with issues of ethnicity and disability, and the relationship between poverty and disability.

Defining disabled children

The most widely used definition of disability is that laid down in the Disability Discrimination Act (DDA) of 1995 (see Box 1). However, consensus on a definition has not yet been reached. The definition used in the Children Act (1989) is based on extremely outdated and derogatory legislation from the 1948 National Assistance Act.* In contrast, the World Health Organisation International Classification of Functioning, Disability and Health (ICF) defines disability as: 'the outcome of the interaction between a person with an impairment and the environmental and attitudinal barriers he/she may face'.³

Box 1: Disability Discrimination Act (1995) definition of disability

'A physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities.'

Models of disability

Ideological debates over the medical and social models of disability are partly to blame for the lack of consensus on a definition. The medical model views disability as a feature of the person, directly caused by disease, trauma or other health condition; (medical) intervention is required to correct the problem with the individual. Many reject this view in favour of the social model. This sees disability as a socially created problem, caused by an unaccommodating physical environment and social attitudes (see Box 2). According to the social model, disability demands a broader political and social response to address this range of issues.⁴ Both these models risk oversimplifying disability, which has both medical and social aspects. However, they do provide a useful way of thinking about the needs of disabled children.

This report adopts the social model as it provides a broader framework within which to examine the variety of issues and needs of disabled children.

Terminology

Throughout this report, the term 'impairment' refers specifically to functional limitations, such as having partial vision. The term 'difficulty' describes problems with behaviour or learning. The use of the term 'disabled children' reflects the view that social, environmental and economic barriers disable children with impairments or difficulties. In this report, 'disabled' means prevented from achieving individual potential. The term 'children' includes children and young people.

A range of other terminology is used to differentiate between types of impairment and the severity of impairment. Impairment can be broadly categorised as physical, sensory (hearing or visual) and cognitive (including behavioural). Some children have more than one type of impairment.

Terms such as severe, complex, multiple, profound, additional or special needs are used to indicate degree of disability. No clear definitions exist for these terms. This report uses the terms 'severely disabled children' or 'children with complex needs' to refer to the sub-group of disabled children with the most severe impairments.

Box 2: Impairment and disability

'Impairment is what we have. Disability is what we experience.'

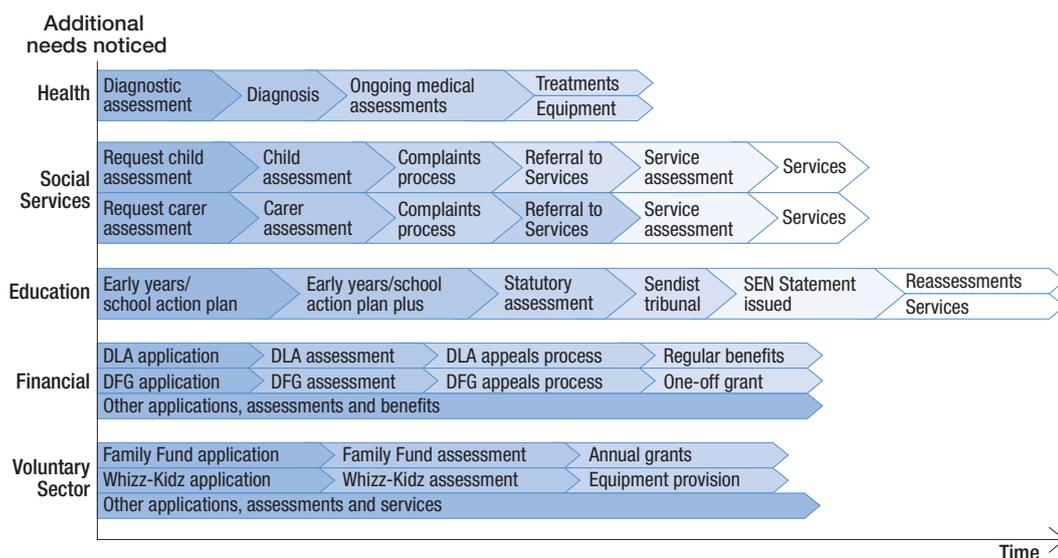
*Social model approach developed by disabled people in 1981 (International Year of Disabled People)*⁵

What happens when a child is disabled?

When a family first identifies that a child may have an impairment, they have to go through a complex process to get a diagnosis and access services. Children and their parents face a barrage of assessments by professionals, forms to fill in and meetings to attend. This all happens at a time when parents may be feeling a sense of shock and grief. This complexity continues throughout the child's life. Many families are constantly dealing with assessments, bureaucracy and appointments, often without receiving adequate services as a result. Some of the agencies and assessments are shown in Figure 2 and discussed in detail throughout the report.

* National Assistance Act definition of disabled: 'a child is disabled if he is blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed; and in this Part — 'development' means physical, intellectual, emotional, social or behavioural development; and 'health' means physical or mental health'.

Figure 2: Processes occurring when a child is diagnosed as disabled*



‘She really needs a multidisciplinary assessment. She has never had one, and she is nine years old. It’s all been done piecemeal, in dribs and drabs, over far too long a time period, and I just think it’s wasted time really. The fact that the only times the different disciplines have talked to each other is when I have nagged them into doing it, seems wrong to me. I find this amazing. I don’t understand why health and education can’t talk to each other about the same child. Why is that so difficult?’ Parent ⁶

Counting disabled children

This section reviews available data on the population of disabled children in the UK.

Why do we need to know?

It is important to understand the numbers of disabled children and the types of impairments they have, in order to plan and provide services. Tracking figures over time reveals trends and changes in the demographics of disabled children. This is useful when planning for future needs. Comparing data identifies where needs are not being met and where additional resources should be placed.

Data on disabled children in the UK is poor. This reflects the lack of consensus on definitions. Also, many people with impairments do not consider themselves (and therefore do not report themselves) to be disabled. Although disability registers exist in some local authorities, there is no national standard, and

no incentive to keep them up to date. Consequently, they provide poor quality data. Comparability of data from different sources is limited because it is collected for different reasons. It may have different age or geographical cut-offs, or include only certain types of impairments.

Number of disabled children

Every day, 75 children in the UK are born or diagnosed with a disability.⁷ Based on data from the Family Resources Survey, the Department of Work and Pensions (DWP) estimated that in 2002 there were 700,000 disabled children in Britain.⁸ Disability was defined according to the DDA definition and children included 0–16 year olds and 16–18 year olds living at home and in full-time education. According to this data, 7% of boys (400,000) and 4% of girls (300,000) are disabled.⁹

The 2001 General Household Survey (GHS), carried out by the Office for National Statistics (ONS), estimated there were 789,000 children under the age of 16 with an ‘estimated long-standing illness, disability or infirmity that limits their activity’.¹⁰

Analysis of DWP survey data (the 2002 Families and Children Study) by researchers at the University of Lancaster used a broader definition of disability. The results suggested that a staggering 10% of all children are disabled. This equates to just under 1.2 million children under the age of 17 in Britain.¹¹

There are 700,000 disabled children in the UK (5% of all children).

* Note that this figure is a simplification of the process, which is likely to be non-linear and contain multiple assessments by the same professionals. The exact process will depend on the child’s specific needs and the way local services are organised.

Before these estimates were issued, policy-makers and charities commonly used a figure of 320,000 disabled children (up to age 16). This comes from a 1984 survey by the Office of Population Censuses and Surveys (OPCS) which was reanalysed in 2000.¹² Despite the availability of annually updated GHS data, policy-makers continued to use this out-of-date underestimate, which suggests a lack of serious political commitment to the issue.

The huge difference between these estimates arises mainly from the different definitions of disability used (See Appendix 1 for a summary of estimates). NPC has used the DWP estimate of 700,000 disabled children throughout this report.

Types of impairment or condition

There are about 8,000 inherited disorders and thousands of non-inherited medical conditions.² It is difficult to break down estimates of disabled children by impairment or condition because many have more than one condition, have no diagnosis, or one which changes over time. However, some data is available to give a more detailed picture.

Areas of difficulty

The DWP estimate of 700,000 disabled children can be broken down by 'area of significant difficulty' (see Table 1). The most common areas are mobility, communication and learning, (with the possibility of some overlap). Data from the Families and Children study can also be broken down by impairment (see Table 2).

Comparisons of data from different sources cause confusion. In some respects (such as learning difficulties) the breakdown shown in Table 1 matches earlier data from the Department of Health White Paper on learning disability 'Valuing People'.¹⁴ In other respects (such as mobility impairments) the breakdown differs markedly from the 1984 OPCS disability

surveys (even allowing for the latter's much lower aggregate figures). The lack of clear and accurate figures across data sources reinforces the impression that understanding the numbers and types of disabled children has not been a priority for the government.

Severe disability

The Family Fund (FF) is a government funded charity that provides grants to the families of severely disabled children. Information gathered by the FF provides the only detailed data available on the conditions of a substantial subset of disabled children. It uses 58 main classifications of conditions, each with up to 50 further specific sub-conditions, to categorise children whose families apply to the fund. The data is biased towards more severe conditions, and is also skewed towards families on lower incomes, because the FF has an income threshold for supporting families.

The top three conditions, accounting for over 35% of applications, are learning disability, autism and cerebral palsy. The ten most common conditions among families applying to the fund have remained the same over the past five years, as has their relative ranking (see Table 3). Recently, the FF has seen increases in applications from families of disabled children with these conditions. The biggest increase between 1999 and 2004 was from families of children with autism (84% increase), behaviour disorders (71% increase) and heart disease (46% increase).

Families still awaiting diagnosis make up the largest group among families applying for the first time (14%, over 1,600 families). Having a diagnosis can give a good indication of how a child may or may not develop. Without one, it may be difficult to obtain services and benefits. Living without a diagnosis also places additional stress on family members.

There are about 8,000 inherited disorders and thousands of non-inherited conditions.



Photograph supplied by Choices

Table 1: Areas of significant difficulty among children, DWP Family Resources Survey 2002 ^{9, 13}

Area of life where child has significant difficulty	% of disabled children affected	Numbers of children affected*
Mobility — moving about	43	300,000
Communication — speaking, listening, reading, writing	43	300,000
Learning, understanding, memory, concentration	43	300,000
Understanding when in physical danger	29	300,000
Other area of life	29	200,000
Lifting, carrying or moving everyday objects	14	100,000
Manual dexterity — using hands for everyday tasks	14	100,000
Continence	14	100,000

*Children may have more than one area of significant difficulty, therefore total is greater than 700,000.

Quantifying the number of disabled children has not been a priority for government.

Table 2: Impairments in children, Family and Children study 2002 ¹¹

Impairment	% of disabled children affected	Approximate numbers of children affected*
Intellectual disability	45	536,400
Chest/breathing problems	28	337,200
Physical impairments	18	212,400
Skin problems/allergies	13	156,000
Stomach/liver disorders	6	68,400
Hearing impairments	5	64,800
Epilepsy	4	42,000
Mental illness	3	37,200
Visual impairment	3	34,800
Heart problems	3	33,600
Diabetes	3	33,600
Congenital birth defects	3	31,200

*NPC calculation: percentage applied to total number of disabled children (1.2 million in this study). Children may have more than one impairment, therefore total is greater than 1.2 million.

Table 3: Ten most prevalent conditions among families applying to the Family Fund, 1999/2000 to 2003/2004¹⁵

Condition	Number of applications per year		% of total applications by condition 2003/2004*
	1999-2004 average*	2003/2004	
Learning disability	7,733	8,833	15
Autism	5,590	6,035	10
Cerebral palsy	4,785	5,914	10
Behaviour disorders	2,976	3,362	6
Down's syndrome	2,657	3,263	6
Deafness/hearing impairment	2,049	2,192	4
Central nervous system disorder	1,983	2,084	4
Epilepsy/convulsions	1,613	1,848	3
Global developmental delay	1,379	1,624	3
Heart disease	1,235	1,471	3
Pending diagnosis	n/a	1,897	3
TOTAL	n/r	38,523	67

*NPC calculations based on Family Fund data.

There are up to 6,000 technology-dependent children in the UK.

Technology-dependent children

The term ‘technology-dependent’ describes children who use one or more medical devices to compensate for the partial failure or loss of a vital body function. Devices include dialysis machines, ventilators, feeding pumps and suction machines. These children require a technically skilled carer to look after them, either a professional or a trained parent or carer. In 2001, it was estimated that there were 6,000 technology-dependent children in the UK.¹⁶

Some technology-dependent children have chronic respiratory problems and require continuous mechanical ventilation. In 1997 a national database to register the number of these children was set up; 136 children under 16 years were registered. This figure rose to 241 children in 2000, an increase of 77% in three years. Medical advances mean that more infants and children survive diseases, accidents and genetic conditions that were previously fatal. The number of children requiring long-term ventilation is expected to grow significantly.¹⁷ Many of these children also have additional care needs, such as help with feeding, toileting and mobility.

Children with life-limiting conditions

Life-limiting conditions are those for which there is no reasonable hope of cure and from which children will die, either during childhood or in early adulthood. Having such a condition brings with it medical and emotional complications which add to the burden of disability and ill-health. Many life-limited children are also disabled. Life-limited children and their families have additional needs, which are explored in detail in *Valuing short lives* (2005).

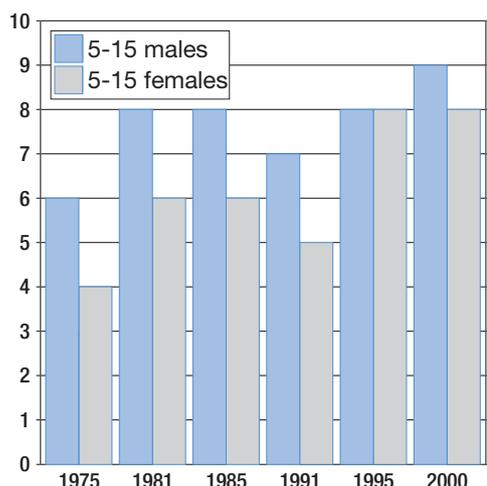
In England and Wales, 5,535 people under 24 die each year, over 60% (3,435) from natural causes.¹⁸ The biggest ‘killers’ (but each accounting for less than 25% of deaths) are cancer, perinatal conditions and congenital abnormalities, conditions relating to the nervous and musculo-skeletal systems, and organ failure. These children have long-term needs. Although the number of deaths per annum may be small, the number of cases needing care at any one time is much higher. NPC estimates that there are 25,000 children under 19 with life-limiting conditions in the UK.¹⁹

Prevalence and trends

Over the past few decades, the incidence* and prevalence[†] of disability in children has increased. The Office of National Statistics (ONS) used data from the FF and the GHS to compare changes in mild and severe disability among 0–5 year olds and 5–19 year olds in the UK between 1990 and 2000.²⁰ FF data was used to estimate severe disability. The GHS data was used to estimate mild disability. The analysis showed that between 1990 and 2000, the incidence of severe disability increased from 6 to 8 per 10,000 population. The incidence of severe disability in boys increased from 7 to 11 per 10,000 population. Among girls the figure fell slightly from 6 per 10,000 in the mid-1990s, to 5 per 10,000 in 2000.

Over the same period, incidence of mild disability increased from 17 to 18 per 10,000 population. Again, this masks a different rate of change in mild disability between the sexes. When viewed over a longer time period, trends in the GHS data show a broadly similar pattern of increases in mild disability. Between 1975 and 2000, prevalence of limiting long-standing illness increased from 2% to 4% in females and from 3% to 4% in males aged 0–4 years old (see Figure 3). In older children, prevalence increased from 6% to 9% in boys and 4% to 8% in girls (see Figure 4).

Figure 3: Prevalence of limiting long- standing illness (mild disability) in children age 0–4, 1975–2000 (selected years)¹⁰



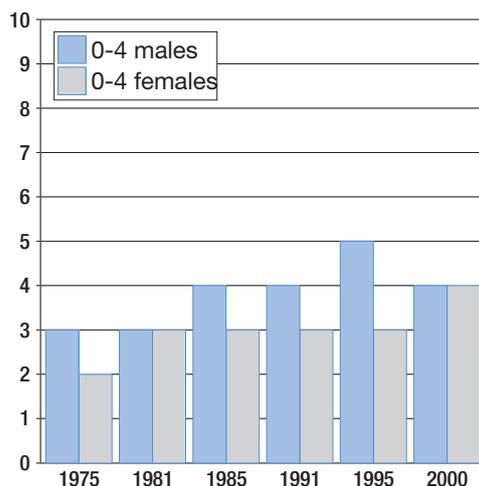
Box 3: Very premature babies and disability

Recent medical advances have increased the survival chances of premature babies. The Epicure study followed very premature babies (those born at 25 weeks gestation or less) born in 1995, at birth, one year, two-and-a-half years, and six years of age.²⁴⁻²⁶ The children were given a range of neuro-psychological tests to establish their development relative to children born at full term. The study found that only 308 (24%) of 1,289 live born very premature babies survived to six-and-a-half years. Of children who reached six, 46% had no problems, 29% had low normal or mildly impaired development, 10% moderate impairments and 14% were severely disabled. Although no directly comparable data is available, around 2% of the general population score in the moderate to severe impairment range using the same tests.²⁷ It is possible to conclude that the prevalence of disability in very premature babies is markedly higher than in the general population.

The study demonstrates for the first time the prevalence of disability among very premature babies. It provides some of the previously absent data that parents and doctors need to make decisions about a very premature baby. These decisions are emotionally charged and present ethical dilemmas. If society chooses to spend large amounts of money keeping very premature babies alive**, then it must guarantee that adequate services and financial support are available to meet the lifetime care needs of that child.

Prevalence of disability is increasing.

Figure 4: Prevalence of limiting long- standing illness (mild disability) in children age 5–15, 1975–2000 (selected years)¹⁰



* Babies being born with an impairment, children being newly diagnosed with, or acquiring, a disability in a given time period.

[†] Disabled children as a percentage all children.

** It is estimated that it costs £330,000 to establish and run each new neonatal intensive care cot. Specialised transport services needed to support neonatal services can cost around £1 million to establish and another £1 million per year in running costs.²⁸

Although prevalence of disability is increasing, the causes of this are not fully understood.

Evidence suggests that the prevalence of disability is rising (NPC could not find evidence of the statistical significance of this increase). This may be for a combination of reasons. Advances in neonatal and medical care mean that more disabled children with complex multiple disabilities and rare conditions are surviving (see Box 3) and life expectancy is increasing.²¹ Automobile design factors (e.g. airbags) have also increased the survival rates of people suffering serious injury from road traffic accidents.¹⁷ Changes in detection and diagnosis of certain conditions may also contribute to increasing prevalence. For example, it is not possible to tell if the increase in the number of children diagnosed with autistic spectrum disorders²² is because of changes in diagnostic practices or an increase in the actual number of autistic children.²³



Photograph supplied by Merseyside Access to Play

Ethnicity and disability

Data on the ethnic origin of disabled children in the UK is poor; however the Family Fund (FF) provides some evidence that incidence of disability is higher among certain black and minority ethnic (BME) groups. Families of Bangladeshi (0.8%), Pakistani (3.6%), African (1.6%) and Caribbean (0.9%) ethnic origin were over-represented (% overestimation shown in brackets) in the FF data for 2003/2004 compared to the 2001 Census. However, this data must be interpreted with caution for a number of reasons:

- Not all families provide data on their ethnic origin, which may introduce bias.
- The total proportion of BME families in the Census represents all income levels, whereas the total proportion of BME families applying to the FF are, by definition, from a lower income bracket (FF only awards grants to families with income below a given threshold). Therefore, BME families may be over-represented in the FF data because they are poorer, not because of a higher incidence of disability.
- Populations of BME groups may have also changed between 2001 and 2003/2004, making strict comparison with 2001 census data invalid.

A more recent and less biased study found no significant associations between ethnicity and risk of disability. Again, a lack of data on ethnic origin for children in the study means the results should be interpreted with caution.¹¹ Additional data and analysis are required.

There is some evidence that certain ethnic groups — Indian, Pakistani, Bangladeshi and Chinese — are less likely to report disability.²⁹ This is of great concern because it means children from these backgrounds receive fewer services. Another challenge for service providers is ensuring that information and publicity material is in appropriate languages. Although there are uncertainties surrounding the prevalence of disability among BME groups, it is known that they are disproportionately poorly served and supported (see Section 2).

Poverty and disability

Poverty and disability are linked. The relationship may work both ways, but disability is more likely to cause poverty than the other way around.

There is no evidence that genetic conditions are related to poverty. However, children born to low income families are more likely to be of low birth weight, which is sometimes related to higher risk of future health problems, including slower development of motor and social skills.²⁹

However, the strength of the evidence is unclear. In the case of moderate learning difficulty there is evidence of a link between higher incidence and lower socio-economic status.¹⁴

There is clear evidence that disability causes poverty. Families with children with long-standing illnesses have lower incomes, because parents may be unable to work due to caring responsibilities. There is a large amount of data showing that families with disabled children are poorer. This is not just because of low income, but also high necessary expenditure. Income is often used to indicate poverty, but alternative definition links poverty to necessary expenditure. Families with disabled children typically have both low incomes and high necessary expenditure (Section 2 examines this further).

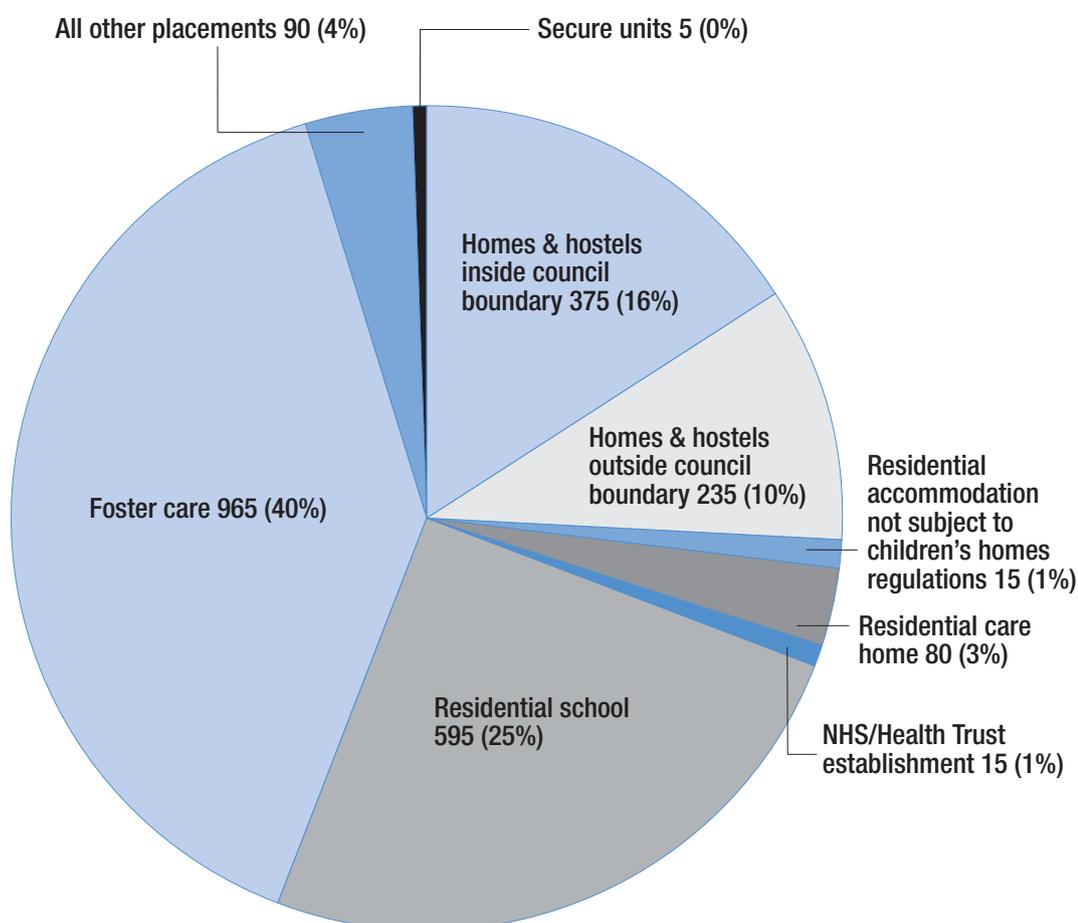
The relative strengths of these relationships are encouraging: funders and policy-makers can more easily influence poverty than the incidence of disability. It should be possible to break the links from disability to poverty.

Places of residence of disabled children

Estimates suggest that between 85%³⁰ and 98%³¹ of disabled children live with their families (including long-term foster families). Some live in residential schools or care homes for long periods of time. Data on the numbers of children and length of time spent in each setting is not available because this information is not routinely collected. However, a recent study provided a snapshot of the location of disabled children in residential placements in England on a single day in 2002 (see Figure 5). Out of a total of 2,380 children, 40% were in foster care, 25% were in residential school and 15% were in an NHS establishment.³² These figures show the use of residential care for disabled children on a single day, and it is likely the total number of children placed during the course of a year will be greater. The figures exclude children under a series of short-term placements; a large proportion of disabled children would fall into this category.³²

98% of disabled children live with their families.

Figure 5: Snapshot of looked after disabled children on a single day (number and %)³²



Data on children in residential schools is routinely collected for special educational needs (SEN) rather than disability, but there is a large overlap. There are about 10,500 pupils in residential special schools.³² Nearly all of them have formal statements of SEN. However, data is not collected on disability. The biggest single group in special schools is teenage boys with emotional and behavioural difficulties. Increases in the number of children with complex needs are likely to lead to increased demand for full-time residential care placements, which are already overstretched.

Data on admissions to healthcare settings does not specifically identify disabled children. The most common reason for admission of children who spend long periods in hospital is categorised as ‘mental and behavioural disorders’. Many of these children are likely to be disabled. In the last three years, 2,200 children spent over six months in hospital; 245 of them spent more than five years in hospital.³²

Disabled children in residential settings are particularly vulnerable to abuse for a number of reasons. It is also more difficult for disabled children to report abuse.^{32, 33} A future NPC report will examine child abuse in more detail.

Section summary: data on disabled children

There are an estimated 700,000 disabled children in the UK.¹³ The most common impairments affect communication, mobility and learning ability; the most common severe disabilities are learning disabilities, autism and cerebral palsy. The majority of disabled children live with their parents; however a significant, yet un-quantified, minority live in residential schools, children’s homes or NHS facilities. The number of disabled children is increasing, in part because of medical advances.

The wide variety of impairments, and lack of consensus on a definition of disability, means that the quantitative data on disabled children is poor. Consequently, key issues, such as the relationship between disability and ethnicity, and between poverty and disability, are not fully understood. Evidence suggests that the causal relationship between disability and poverty is far stronger than the one between poverty and disability. It also suggests that incidence of disability does not differ markedly between ethnic groups, although BME families are less likely to receive appropriate support. The lack of systems in place to identify and record disabled children, and failures to use existing data, show that policy-makers and service planners give a low priority to the needs of disabled children.

Key issues such as the relationship between poverty and disability are not yet fully understood.



Photograph supplied by Merseyside Access to Play

Children

The needs of disabled children include friendship, leisure and play, holidays, equipment, transport, communication and education. Most of these are common to all children. However, disabled children are often prevented from fulfilling their needs because of inaccessible or poorly designed services, ignorant attitudes and parents' financial circumstances. Charities can meet these needs. They lobby to improve services and support disabled children to overcome barriers that prevent them from enjoying ordinary childhoods.

The UK has signed up to the 'UN Convention on the Rights of the Child'. This sets out children's rights to family life, freedom of expression, education and protection from abuse. The rights of disabled children are specifically addressed in this convention (see Box 4). Many disabled children do not get to enjoy their rights, simply because they are disabled. This is wrong. Action must be taken to ensure that all disabled children can enjoy the things that make childhood special.

Box 4: UN Convention on the Rights of the Child

'[...] a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.'

Children's needs

Friendship, leisure and play

All children deserve and need to make friends, play and take part in leisure activities and hobbies. For young children, play is part of learning and development. For older disabled children who are socially isolated because they don't attend school or live far from school friends, the availability of leisure activities is crucial. Disabled children are denied leisure activities that many of us take for granted.

What is the situation?

Barriers to leisure and play

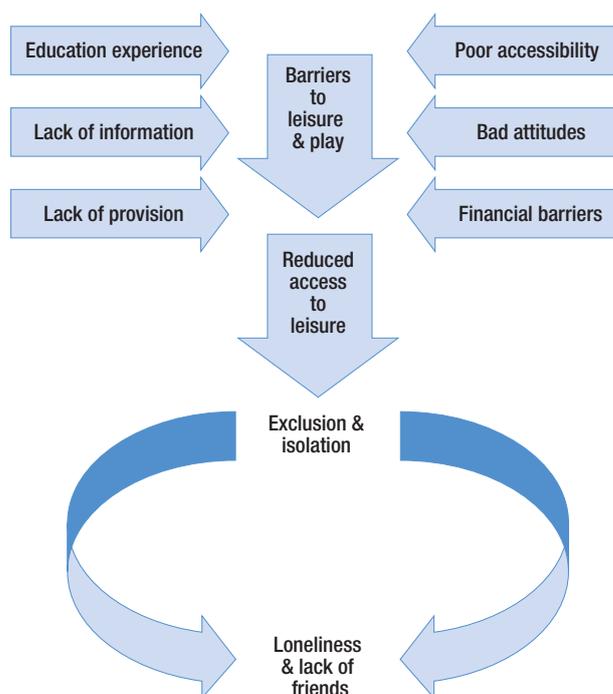
Many barriers to leisure, play and making friends are put in the way of disabled children. Mainstream leisure and play facilities are failing to meet the needs of disabled children. This increases the need for specialist provision. Disabled children face the following barriers:

- Lack of friends and appropriate supporters.
- Lack of provision and information about services.

- Accessibility problems ranging from bad attitudes to lack of toileting and changing facilities.
- Experience of education.
- Financial barriers.
- Exclusion from popular culture.

These prevent disabled children from having friends as well as happy and fulfilling social lives. Allowing barriers to persist creates and reinforces loneliness and social isolation (see Figure 6). Because leisure activities are an opportunity to make friends, preventing disabled children from accessing them deprives them of friendship. Removing or easing these barriers should be a priority.

Figure 6: Impact of barriers to leisure and play



Friends and supporters

Disabled children consistently say that leisure and play, after school, in the holidays and at weekends, are the most important missing elements in their lives.³⁴ They feel frustrated that legislation is frequently ignored. Young people identify leisure as a crucial way to have fun and make and sustain friendships. Being with friends is a leisure activity in itself and taking part in leisure activities with friends, not surprisingly, enhances the enjoyment. Disabled children enjoy the same types of leisure activities as their non-disabled peers. These range from watching TV, to playing outside and going to the cinema or bowling.³⁵

“I am excluded from so much and I am so lonely and have few friends.”
Disabled young person³⁶

My daughter has never been invited to a birthday party, or to anyone's home to play.

Parent ³⁷

My seven year old daughter is in nappies and the only solution is to lay her on the floor of the disabled toilet. I hate having to put her onto the floor of a public toilet.

Parent ³⁸

Having no friends, or none that live close by, prevents children enjoying group activities. This becomes a self-perpetuating situation of loneliness and isolation.

For teenagers, having an adult supporter (personal assistant or volunteer) or parent with them at all times is embarrassing. At the same time, having no supporter may prevent them being able to go out without their parents.

'The biggest barrier is that I'm not allowed to go out on my own or with my friends. There is always an adult with us.'

Disabled young person ³⁶

Lack of information and provision

In a recent survey by the charity Contact a Family*, 27% of parents reported their child had not joined a local club because of a lack of information. Other parents said it was because they felt that their child's special needs wouldn't be met (66%) and/or that a specialist club would be better (52%). More than half (55%) said that distance and a lack of local suitable facilities was a barrier.³⁸ A lack of age appropriate activities, especially for teenagers is also a problem. Although disabled children want and should (morally and legally) be able to access mainstream leisure activities, they also value opportunities to spend time with other disabled children. There is a strong case for provision of both specialist and integrated leisure and play facilities (see Box 5).

'I have been trying to find Saturday activities for him. There is nothing at all for special needs except one drama group especially for children with Down's Syndrome. I want to weep when I look at all the lists of riding/swimming/drama clubs open to other children, all of which he would enjoy. Normal clubs don't have enough staff to cater for his needs.'

Parent ³⁸

Accessibility and attitudes

Accessibility of leisure and play facilities is about more than physical access. It encompasses provision of adequate toilet and changing facilities, provision and respect for disabled parking areas, and signs and markings for children with hearing and visual impairments. In spite of The Disability Discrimination Act (DDA), Contact a Family found that the majority of leisure facilities had no suitable toilet and changing rooms. Queues are boring and frustrating for most children, but they are particularly distressing for children with autism or behavioural problems. The possibility of having to queue for a long time can prevent access. Contact a Family found that 73% of families were daunted by long queues.

Attitudinal barriers also prevent disabled children from enjoying normal activities. Frequently, disabled children and their families face a lack of common courtesy and respect. Contact a Family found that almost 70% of families were put off visiting leisure facilities because of being made to feel uncomfortable. Rigid thinking and ignorance of staff were a common source of complaint. Disabled children emphasise the importance of feeling welcome and being accepted. They define this as: people being nice and polite, knowing their name, introducing them to other people, making friends and not being nasty.³⁸ All too often, this simply doesn't happen.

'Our son has severe learning difficulties with no communication and inappropriate behaviour. We are prevented from using facilities because other people do not accept our son's reactions.'

Parent ³⁸



Photograph supplied by Merseyside Access to Play

* Contact a Family is a national charity which provides support and advice to families with disabled children.

Box 5: The need for inclusive and specialist leisure provision

Isobel is a single parent of two boys. Ben, aged 13, has cerebral palsy and Nick, aged 11, has autistic spectrum disorder. Ben attends a mainstream school and Nick attends a special school. Nick needs constant supervision and Isobel receives some support from social services. Nick stays at a residential short break unit for three nights a month and attends a Saturday club for three hours a fortnight. Isobel has been offered one further overnight stay and two extra days during the school holidays, but not at times that are suitable for the family. Isobel runs the summer holidays like a military campaign. She describes it as 44 days of being organised. Ben and Nick have distinct needs. Ben needs more rest and Nick needs to be active. This year Nick will attend a play scheme for two weeks for children with severe learning disabilities. Ben, who is more independent, will probably attend activities run by the youth service and will spend time with friends. He will also take part in activities for disabled people at an outdoor centre, including archery, sports and crafts.

Barnardo's³⁹

Experience of education

Experience of education has a profound effect on children's social lives. Children in special schools often live far away, making it harder to socialise with school friends outside of school. They may also lack confidence to socialise with their non-disabled peers because they have not had the opportunity to do so in school. Disabled children in mainstream schools are often treated differently to other children, which makes it harder for them to interact socially. For those children who feel isolated in mainstream schools, participation in leisure activities can be a lifeline.

'It's a bit harder being out in the real world after special school.'

'Mainstream schools treat you differently to the other students.' Disabled young people³⁶

Financial barriers

Families with disabled children often have low incomes and face higher costs (see Section 2). When money is tight, leisure activities may be the first things to be sacrificed. Few leisure facilities have reduced charges for disabled children and their carers.³⁸ Even where they do, parents or children feel embarrassed at having to explain the nature of 'invisible' disabilities in order to claim them. Unsuitable and expensive public transport may force disabled children to rely on taxis. For many, this is unaffordable. In the Contact a Family survey, almost 50% of families reported that budget constraints limited their access to leisure; 25% reported that they couldn't take their children to activities because of lack of suitable transport.³⁸

Exclusion from popular culture

Sensory impaired children are excluded from popular culture, such as books and music. This makes it harder for them to make friends based on shared enjoyment of these activities. For visually impaired children there is a delay between the publication of popular books, such as the Harry Potter series, and their availability in large print. This means that by the time they can participate in discussion and play related to it, other children are no longer interested.

Watching and participating in sport is an integral part of popular culture, and one which disabled children are often excluded from. Sport England

sent a questionnaire in 1999 to 5,600 disabled children and young people aged 6–16 years. Almost 50% responded. Although most participated in sport, they did not participate as much as other children or as much as they wished. The most common barriers were: lack of money, health considerations, unsuitability of local sports facilities and having no one to go with.⁴⁰

Constraints to service provision

Service providers may not be able to afford to run services for disabled children who have greater support needs than the usual staff to child ratio. However, not all disabled children have such needs. Difficulties in finding suitable premises, obtaining insurance and staffing difficulties (recruitment and retention) also prevent service providers from offering play schemes to disabled children. Lack of coordination between schemes may mean that timings overlap, resulting in reduced opportunity. Many services are unable to offer flexible access on a needs basis.³⁹ The result of all these factors is inflexibility, rationing and under-provision of essential play and leisure services for disabled children. Erroneous or overzealous interpretation of health and safety laws by service providers can also result in exclusion of disabled children from play and leisure activities. Recognising this, the Health and Safety Executive has supported the following statement by the Play Safely Forum:

*'All children both need and want to take risks in order to explore limits, venture into new experiences and develop their capacities, from a very young age and from their earliest play experiences. Children would never learn to walk, climb stairs or ride a bicycle unless they were strongly motivated to respond to challenges involving a risk of injury. Children with disabilities have an equal, if not greater, need for opportunities to take risks, since they may be denied the freedom of choice enjoyed by their non-disabled peers.'*⁵

Adapting playgrounds and leisure facilities to suit the needs of all disabled children is not possible. However, it is not necessary (either and should not be used as an excuse to close down non-accessible facilities). The most important barriers are often attitudinal or environmental ones that can easily be rectified.

I had to stop taking my son to school club once a week as it cost me too much money in a taxi to collect him. I want him to have a normal life; I feel his childhood is slipping away...

Parent³⁸

Environmental and attitudinal barriers can often be easily rectified.

What is the government doing?

The Audit Commission's evaluation of the Quality Protects initiative* found improvements in the quality and availability of services for disabled children, particularly in early years play and leisure services.⁶ However, there is still a national shortage of inclusive and specialist provision, with many initiatives subject to short-term or insecure funding.³⁹

Local authorities are no longer required to ring-fence⁷ funding for disabled children's services. This threatens improvements brought about by the Quality Protects initiative. Similarly, cuts to the Children's Fund are likely to mean a reduction of inclusive play facilities, many of which take place during summer holidays when there is a greater need for activities. For example, in Liverpool, the Children's Fund funded 61 projects (not all for disabled children) in its first round, which was cut to 30 in the second round.⁴¹ On a more positive note, £200 million of National Lottery funding has been earmarked for new and improved children's play facilities. The government has drawn up a national strategy on how the funds will be spent, paying particular attention to the needs of disabled children (although none of the money is ring-fenced for disabled children specifically). Charities will play a vital role in delivering leisure and play services funded by this money.

Various pieces of legislation recognise the importance of play and leisure, and the need to ensure that leisure opportunities are inclusive and accessible to all children (see Box 6). However, this is not yet having the impact needed for disabled children. Local and national government need to do much more to uphold these laws.

Disability awareness and inclusiveness training for staff working in leisure and play services are an important start in breaking down negative attitudes. Staff turnover means that training must be regularly repeated. A number of charities provide inclusiveness and disability awareness training funded by statutory sources. However, adequate follow-up after training is vital to ensure that attitudes have really changed and that the service is not turning people away or treating them poorly. This is the role of the statutory sector, which should have inclusiveness policies at the local level that are enforced in all services. Where these policies are not in place or not being actioned, there is clearly a role for local and national lobbying.

Compliance with Part III of the DDA, relating to physical barriers or lack of essential facilities (e.g. accessible toilets and changing facilities), is poor. A recent survey by the charity Scope found that only 18% of leisure facilities were fully accessible.⁴² In the long-term, the threat of legal action and poor publicity may encourage facilities to improve accessibility. Unfortunately the phrase 'reasonable adjustment' weakens the power of the DDA. It creates confusion, even among those who wish to make their facilities accessible. There are no clear specifications laid down to ensure a minimum standard for new buildings. Local authorities can improve this by ensuring that all of their premises are accessible, and checking that planners do everything possible to help businesses improve access to their premises. They could also consider making DDA compliance a condition of being granted licences and other local authority permissions.⁴²

The Office of the Deputy Prime Minister (ODPM) recently commissioned its own research into developing accessible play space. The resulting good practice guide highlights the importance of play for all children and the need to consult and engage disabled children and their families.⁴³ It gives useful advice, information, examples, resources and contacts. However, it is criticised for an emphasis on developing new playgrounds and the importance of technical design to overcome barriers; it pays less attention to other barriers, such as attitudes of other parents or children, bullying and cost. Guidance on these issues is provided in a National Playing Fields Association report.⁵ It is the responsibility of local authorities to use these guidelines and implement appropriate policies.

Box 6: Legislation on leisure and play

The Children Act (1989) recognises that '*children's need for good quality play opportunities change as they grow up, but they need such opportunities throughout childhood to reach and maintain their optimum development and well being*'. The Act says that local authorities should provide services to minimise the effect of disabilities on the lives of disabled children and give them opportunities to lead as normal a life as possible. Authorities must also promote access for all children to the same range of services.

The Disability Discrimination Act (1995) makes it unlawful to discriminate against disabled people. It requires service providers to 'make reasonable adjustments' to policies, practices and procedures that discriminate. Part III of the Act has recently come into force. It covers indoor and outdoor adventure playgrounds, leisure centres, play areas in public parks and playgrounds. Service providers may have to consider making permanent physical adjustments to their premises.

The Special Needs Education and Disability Act (SENDA) (2001) places a duty on all education providers in Wales, England and Scotland to ensure that they have made reasonable adjustments to include a child with a disability or special educational need within a mainstream setting. The focus is on schools to include disabled children in all aspects of school life. Schools have to justify not including disabled children on school trips, holidays and when accessing leisure opportunities.

Article 31 of the UN Convention on the Rights of the Child recognises '*the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child, and to participate freely in cultural life and the arts*'.

* Quality Protects was a government initiative aimed at improving services for vulnerable children (see Appendix 3). It ended in 2004.

⁷ Restrict the use of money for a specific purpose.

In summary, the government is making efforts to improve access to leisure and play services for disabled children, but the pace of change is slow and more needs to be done. Having legislation in place is not sufficient to drive change. Lobbying and advocacy by and on behalf of disabled children is vital to ensure that improvements happen soon. Without this, disabled children will continue to be excluded from the leisure activities that other children take for granted.

What is the charitable sector doing?

Sometimes disabled children need the support of a friend or volunteer buddy to enable them to participate and enjoy leisure and social activities.

There are a number of charities involved in supporting disabled children in this way.

Mencap's 'get together' campaign trains volunteers to help children with learning difficulties go to out-of-school clubs. The charity **Out and About** uses volunteers to help disabled children and young people access a range of mainstream leisure activities, from Brownies to art galleries. The **National Autistic Society** runs a volunteer befriending scheme for people with autism.

Circles Network supports disabled people to build social networks to ensure that they have an active social life. They work with children in and out of school to help them build confidence and friendships that last many years. **Write away** is a charity that helps disabled and non-disabled children communicate and make friends through letters, Braille and audio tapes.

Another approach is to place a trained staff member or volunteer in a mainstream leisure facility so that children with additional needs can attend without the stigma of having an adult with them. **Merseyside Access to Play** supports disabled children to access local mainstream leisure and play facilities in this way. It also provides inclusiveness and disability awareness training for a range of organisations and leisure facilities.

Charities play a crucial role in providing information about inclusive and specialist leisure services locally and nationally. A number of them do this via factsheets and websites including **Contact a Family**, **Kidsout**, and **Artsline**, who have an on-line directory on the accessibility of London-based arts venues.

Charities often provide leisure services for disabled children, although many of these are wholly or partly funded from statutory sources.

The Attlee Foundation runs inclusive play projects, a youth group and a range of after school leisure activities in Tower Hamlets. It is currently building a multi-purpose facility to provide a range of play, sport, leisure and learning facilities for children with and without special needs. **Barnardo's Spark Centre** in Tower Hamlets provides a range of services, including an under-fives play and activity service for disabled children and a community based Saturday activity programme for children with autism. **Kids** provides play schemes, youth clubs and befriending services for disabled children. It recently merged with **Kidsactive**, which runs adventure playgrounds for disabled children.

Half Moon Young Peoples Theatre Company in Tower Hamlets produces plays and runs drama projects in schools and the community that are fully inclusive and cater for a range of needs and abilities. **Oily Cart Theatre Company** puts on plays and performances for children with learning difficulties and/or sensory impairments in schools, nurseries, theatres and community venues. **Epic Arts** in Tower Hamlets runs integrated arts workshops (dance, music, poetry, art) for disabled and non-disabled people.

Toy libraries are an excellent way for children to access a wide variety of specialist toys — often more expensive than non-specialist toys. They usually provide support for parents to help them learn how to get the best out of play with their children. These are generally funded from statutory sources, with some charitable income.

Charities play a crucial role in providing information about inclusive and specialist leisure services.



Photograph supplied by Merseyside Access to Play

It's cool that we're friends – we can learn from each others differences!

Young person ⁴⁴

I am getting quite a lot of help at school. Recently I had decided to have no help in two of the lessons and right now my friend helps me in those lessons.

Disabled young person ⁴⁵

The **National Association of Toy and Leisure Libraries** is a national umbrella body providing information and support (e.g. toy appraisals, disseminating best practice) to toy libraries throughout the UK. **Toyhouse Libraries Association of Tower Hamlets** provides support for all toy libraries operating or wanting to set up in the area. It also runs a number of toy libraries with stay and play sessions and a mobile toy library for families who cannot attend the sessions. **PSS Liverpool's Family and Children's Project** runs a toy library with a number of stay and play sessions. **Kidsout** gives grants to fund special toys, terrain buggies, fun days out, holidays and short breaks for parents and disabled children.

The **National Blind Children's Society** produces bespoke copies of popular children's books for visually impaired children, through its 'CustomEyes' programme, charging only the recommended retail price. It also negotiates with publishers to try and make books available for customisation pre-publication, so that visually impaired children don't have to wait to get them. It produces curriculum and revision guides for visually impaired children for purchase by local authorities. **RNIB** also has a talking book service and the charity **Listening Books** has a range of educational publications available on audio format.

Local authorities are responsible for providing a broad range of leisure facilities for young people, but in many instances fail to include disabled children. Lobbying at local level is needed to improve this situation. Disabled children play a vital role in influencing service provision; charities support them to do this. For example, the **Children's Society** produced a CD-Rom 'Ask-us' which consulted with disabled children about what they want. It also has a project that promotes the inclusion of disabled children in play and leisure activities in their own communities.

Contact a Family supports parents to form local groups, which are a potentially powerful way of lobbying for improved services. **Circles Network** runs the Partners in Policy Making training course, which empowers parents of disabled children to lobby and work constructively with policy makers to improve services. **Scope** is campaigning for improved access and facilities for disabled people, particularly in leisure facilities, and enforcement of the DDA.

What are the outcomes of friendship, leisure and play?

Overcoming the barriers that prevent disabled children from accessing mainstream leisure and play facilities is likely to reduce demand for specialist services. However, these should still exist for as long as children and families require them, and until mainstream services are truly inclusive for all.

The benefits of leisure and play for children are intangible and difficult to measure. However, it is every child's right to enjoy a happy and fulfilling childhood. Play is a critical part of learning; it helps children develop and express themselves, use their imagination and understand how things work. For older children, leisure builds confidence and gives them the skills to make friends and develop relationships. Increased opportunities for leisure and recreation for disabled children are important to combat isolation and loneliness. Having friends can help them cope with school and other situations. Friendship and leisure form a virtuous circle: having more friends creates more opportunities for leisure; this in turn helps children increase their social networks and build confidence about what they can achieve.

'I made loads of friends during the summer which always makes me happy. My best friend was Robert.' Disabled young person ⁴⁵



Photograph supplied by Merseyside Access to Play

Encouraging and helping disabled children to interact with their non-disabled peers has additional benefits to those purely arising from friendship. In the long-term, children who interact positively with disabled children are more likely to help change attitudes within society.

Holidays

Holidays are especially important for disabled children and their families simply because their lives are difficult in so many other ways. For disabled children who have limited access to leisure and play, a holiday may be their one opportunity to have fun with their peers. Families often have little time left after work, caring routines and appointments with specialists to enjoy quality family time together. Money is a major constraint; additional costs related to disability and lower incomes for parents mean that a holiday is too expensive for many families – no matter how much it is needed.

There is not a clear distinction between short breaks (see Section 2) and holidays. However, holidays can be different from short breaks in their duration (they are longer), frequency (usually once a year or less) and the fact that holidays can be a family event with all members of a family enjoying time together in a relaxing environment away from the troubles of home and work.

The barriers to having holidays are similar to those described above for leisure and play. They include attitudes, access, environment and finance. There are additional barriers, such as difficulty in finding a travel agent or tour operator able to cater for additional needs and obtaining insurance.

What the government is doing?

The Family Fund (FF) is a government funded charity which provides help towards holiday costs when the family includes a severely disabled child under 16. Grants vary in size and can be used towards family holidays with or without the child. However, eligibility is subject to an income threshold. Another limitation of the FF is that families can apply only once per year. There is a large role for charitable money to help disabled children have independent or family holidays.

What is the charitable sector doing?

Charitable organisations that provide signposting to suppliers and funders of holidays for disabled children and their families include **Contact a Family, Royal Association for Disability and Rehabilitation (RADAR), Holiday Care, National Autistic Society** and the **British Red Cross**.

Merseyside Youth Association's Choices project in Liverpool provides residential holidays for young disabled people in accessible accommodation around the country. Wherever possible it supports the young people on an individual basis after the holiday, to help them access mainstream leisure and social activities. **Activenture** provides one week residential outdoor pursuits holidays for disabled children with a wide range of needs. A young volunteer acts as a buddy and carer. **Afasic** organises activity week holidays for children with speech and language disorders.

What are the outcomes of holidays?

Holidays are about fun, enjoyment and relaxation. A study looking at the benefits of holidays for children in public care (including children with learning difficulties) identified a number of benefits. The most important was that young people recognised that having a holiday was what everyone else did, and therefore felt normal. Other benefits included relaxing, learning new skills, experiences such as sports or activities, a break from routine and educational experiences, such as using different currency, language or tasting new foods. Carers reported increased self esteem, confidence and maturity among young people.⁴⁶

'The holiday is good for you not only for your body, but for everything.'

Young person ⁴⁶

Equipment, communication and transport

What is the situation?

Equipment

Everyone uses aids and equipment to make their lives easier. For disabled children and their carers, aids are vital to make daily activities possible and to give them greater independence. A third of parents with a severely disabled child under two years use more than three pieces of equipment daily to provide basic care (e.g. bath and bed adaptations).⁴⁷ Having the right equipment can also be about human dignity.

Equipment required to enhance independence or meet care needs is usually the responsibility of social services.* This can include aids and equipment to help with lifting and transfer, personal care, eating, bathing and washing. Need for equipment is usually identified by a social worker who refers the case to an occupational therapist (OT) for assessment. Equipment is usually provided on a long-term loan basis. Support provided by OT or social workers may include practical tips and advice on daily living.

Merseyside Youth Association's Choices project in Liverpool provides residential holidays for young disabled people in accessible accommodation around the country.



Photograph supplied by Merseyside Access to Play

* This includes help with arranging adaptations to the home or any additional facilities to secure greater safety, comfort and convenience. Adaptations are covered in the 'Housing and adaptations' section in Section 2.

Delays in the provision of essential equipment impede children's development.

“You are on a waiting list. You get [the equipment]. It's wrong. You send it back. You go back on the list. By the time the right thing's come, his needs have changed.” Parent⁶

Health visitors, district nurses or social workers can provide advice on incontinence and most health authorities have designated incontinence advisors. Once children are past infancy, the health authority can provide incontinence aids, such as bedding protection, disposable nappies, catheters, pants and odour controls. However, some authorities charge for these items.

Aids and equipment for nursing and medical care at home, such as special beds and bed equipment, hoists, incontinence aids, feeding aids and mobility aids, are usually the responsibility of the local NHS Primary Care Trust (PCT). Equipment can be supplied by the NHS on a free loan basis, with items being prescribed by a GP or consultant and/or on the basis of an OT assessment.⁴⁸ Where equipment is needed for social and medical care, in theory, a joint assessment should be carried out by relevant professionals.

Equipment for children with impaired hearing, such as hearing aids, are normally provided, supplied and fitted by the NHS. Children are referred to an audiologist by their GP or picked up by the newborn hearing screening programme. Some parents may prefer to purchase hearing aids privately, but the cost can be prohibitive; modern digital hearing aids cost up to £2000 each.⁴⁹ Aids for children with visual impairments, such as magnifiers or more complex appliances can be prescribed by the NHS. There is also a range of 'environmental aids' to promote independence for hearing or visually impaired children, such as vibrating alarm clocks.

Mobility needs are normally assessed by a physiotherapist via GP referral. The local hospital or community health service can loan basic walking aids. The local NHS wheelchair service provides wheelchairs (electric or manual). It can also supply children's buggies. These services should help families choose a suitable wheelchair to meet their needs, including extra items such as cushions, rests and trays. They are also responsible for maintenance and repairs. Wheelchairs are only supplied to children who need a chair permanently. Theoretically, the NHS wheelchair service can supply any wheelchair. In reality, this depends on local criteria, available resources and the circumstances of the child and family. Families usually have to buy outdoor electric wheelchairs, scooters or specialist sports chairs which can be extremely costly. The average cost of wheelchairs supplied by the charity Whizz-Kidz in 2004 was £6,174, ranging between £1,162 and £17,400.⁵⁰

Evidence shows that the system of assessing and providing disabled children and their families with the equipment they need to help them go about their daily lives at home, school and in the community is not working. In a recent review of services, the Audit Commission found that disabled children and their families face many problems in accessing basic equipment.⁶ They found problems such as:

- inflexible services
- inappropriate equipment
- additional costs to families
- confused eligibility criteria
- shortage of professionals
- waiting lists

Local authorities have different rules governing distribution of this equipment; families frequently do not know what is available. The variety of providers of equipment means it can be difficult for parents, or even professionals, to have a clear understanding of who should provide what. Different providers often wrangle over whose responsibility it is to provide certain equipment. Delays in the provision of essential equipment impede children's development, constrain their ability to participate and cause stress for parents. Sometimes children have outgrown the equipment by the time it arrives — a total waste of money. In 1995, research by the University of York showed that the lives of at least 70,000 disabled children would be significantly improved by the provision of a customised wheelchair or other type of mobility equipment.⁵¹ It is not obvious that matters have materially improved since then.

‘You can have a bed that goes up and down if you don't have a hoist...so because we had a hoist we couldn't have one. So I said, couldn't you let me have a broken one, one that's stuck, because I don't need down, I just need up? And somebody said, ‘Oh yes you can have one’. But then it came back, ‘no...you can't have one. It's not social services who supply the beds, it's nursing something'.... But in the end they sent us bed raisers.’ Parent⁶

Box 7: Common symbols from the Makaton symbol communication systems⁵²**to read****to break****to write****we/us****Communication**

Speech, language and occupational therapy are necessary to help some children communicate and learn to use equipment. Therapy is vital to help children participate in daily life and communicate their thoughts, ideas and feelings. Severely disabled children may need extra support to help them express their likes and dislikes.

A speech and language therapist normally assesses a child and recommends equipment to help communication. Following assessment, a therapist may be able to loan the required equipment. Speech and language therapy is often regarded as educational provision and may therefore be identified in a child's statement of educational needs and funded by local education or health authorities. Parents can refer their child to a speech and language therapist. Some schools arrange for an occupational therapist to assess the child's needs and provide equipment for use at home and school.

In many cases, local education authorities or schools supply aids for use only in the school. This means that when these children go home they cannot take the equipment with them and may be unable to communicate with their families. For example, this may apply to symbol communication systems. Symbol systems augment language and literacy, and can often be vital learning and communication tools for students with physical and communication difficulties (see Box 7). If parents are not trained to use communication systems that their children use at school, it leaves families unable to communicate effectively at home.

The Audit Commission research revealed that services, such as speech and language therapy and physiotherapy, also had strict eligibility criteria as a result of limited budgets, national shortages of trained professionals and long waiting lists. Inconsistencies in the way services were accessed (e.g. referral procedures) prevented people accessing therapy services. Even those families who were assessed as being eligible for services faced unacceptable waits. The research found that waiting for a speech and language assessment can take one year, and waiting for therapy can take another. This means that children are of school age before getting therapy. Their whole school experience is likely to be harmed.

Transport

Disabled children and their families face difficulties in accessing transport; this contributes to their social exclusion. Public transport is often physically inaccessible for disabled children. For example, although 90% of London buses are now accessible, the national average is only around 30%.⁵³ Public attitudes and ignorance may make children feel uncomfortable even if they can physically access public transport.²⁹ Public transport will never fulfil all transport needs, especially for children who are ill. Families with disabled children who don't have a car are often heavily reliant on taxis — an expensive way to travel. Transport needs are often omitted from needs assessments and local authorities are not obliged to provide free school transport for children. Even when transport is provided, it is often inflexible and limits children's freedom to visit friends or attend clubs after school.

'Attempting to travel by train is a real nightmare: getting him on and off trains; flights of stairs and having to leave the wheelchair in the guard's van and carry our 12 year old for the journey.'

Parent ³⁸

What is the government doing?

There are four key policy initiatives aimed at improving specialist equipment and communication services:

- **Integrated Community Equipment Services** implemented by the Department of Health (DoH).
- **Communication Aids Project** established by the Department for Education and Skills (DfES).
- Standards for equipment and therapy services included in the **Children's National Service Framework (NSF)**.*
- **Prime Minister's Strategy Unit** recommendations on equipment and therapy services and individualised family budgets.

I can't always do the things I like, because I always need someone with me and I don't have transport.

Disabled young person ⁴⁵

* The National Service Framework (NSF) for Children, Young People and Maternity Services is a government document which sets out, for the first time, national standards for children's health and social care. Standard 8 deals specifically with disabled children.

Responsibility for provision of the majority of equipment and therapy for disabled children lies in the statutory sector.

The Children's Society has a range of child advocacy projects around the country that help disabled children communicate their ideas.

Other initiatives and measures include:

- A voucher scheme which allows families to pay the difference between the wheelchair available on the NHS and a more expensive one of their choice.
- Children who receive the higher rate of Disability Living Allowance (DLA) mobility component can join the Motability Scheme. Motability is operated by an independent not-for-profit company, and enables people to use their DLA to finance the purchase of mobility equipment including wheelchairs, scooters and cars.
- The Government funded FF also provides grants for families of disabled children to purchase everyday items such as furniture, bedding and white goods. These may be needed because of the child's disability, but are not provided by statutory services. Items of equipment purchased solely for use by a disabled person are zero VAT rated, which can also help to reduce the cost.

These initiatives are welcome responses to problems with the provision of equipment and communication services. However, further measures are needed if disabled children and their families are to get the correct equipment and support at the right time, sparing the pain and anguish of delays, poor services and inappropriate equipment.

Public transport needs to be accessible and more affordable for disabled people. The DDA should help to improve accessibility of transport services. Staff would also benefit from disability awareness training. Disability benefits paid to families should reflect their higher transport costs. Assessments of children's needs should take into account transport needs, to ensure flexible and appropriate provision.

In summary, responsibility for provision of the majority of equipment and therapy for disabled children lies in the statutory sector. However, evidence suggests that services are often poor. Many children and families struggle to cope with inadequate or outdated equipment, or are waiting to receive vital aids. Technology advances quickly; there is always new or more advanced equipment that children could benefit from, but which is unavailable from statutory sources. Families face a stark choice between doing without, or purchasing equipment out of their own pockets. For many, high costs and low incomes mean this is not an option. Even those who can afford equipment may be faced with a bewildering array of products and a lack of expert advice. This means that many disabled children are prevented from participating in daily activities, developing and enjoying independence as fully as they could with the right equipment. Carers have to struggle to provide care with inadequate equipment. Insufficient speech and language therapy leaves many children unable to communicate effectively, making them frustrated and slowing development.

What is the charitable sector doing?

The government is responsible for providing the majority of equipment and communication therapy services. However, not all children are getting what they need when they need it, or are able to take maximum advantage of available technology. Charities have many opportunities to improve the situation in the long-term through lobbying. They can also support families in the short-term, until government services improve. Charities can use private funding to meet equipment and communication needs in a variety of ways:

- Information and signposting.
- Help with cost.
- Loaning or providing equipment.
- Providing therapy and communication tools.
- Training of children, parents and carers in use of equipment.
- Working with professionals.
- Lobbying government.

Afasic supports families and professionals on all aspects of communication difficulties, including information via a website and helpline.

The Children's Society has a range of child advocacy projects around the country that help disabled children communicate their ideas. This can be about something like what they prefer to eat or more important issues such as choice of school. They also train professionals to be able to better understand and work with disabled children in planning and delivery of care.

The British Red Cross has a network of medical loan depots. These can lend aids and equipment, including wheelchairs.

Whizz-Kidz can provide customised mobility equipment (wheelchairs and tricycles) that is not available from the NHS. It also provides training, advice and information. **The Association of Wheelchair Children** provides free training, assessments and advice to help children and young people get the most out of their mobility equipment.

The **National Deaf Children's Society** provides advice and information on all aspects of childhood deafness. It also has a free equipment loan service and fund. The **National Blind Children's Society** provides assessments, advice, installation and technical support on computer hardware and software for visually impaired children to individuals, local education authorities (LEAs) and schools.

The **Disabled Living Centres Council** is an umbrella body for disabled living and independent living centres. Disabled living centres provide free, unbiased advice on a large range of products and equipment to disabled people of all ages through a network of showrooms. The **Disabled Living Foundation** is a charity that provides free advice and information on equipment and assistive technology for independent living to disabled people, carers and professionals. It also has a database of equipment.

Section 3 examines further how private funding can help charities improve statutory equipment and therapy services through lobbying.

Education

All children need education to help them achieve their potential; this is particularly the case for disabled children who may need extra support to reach their goals. There is substantial overlap between issues regarding disabled children in education and the field of special educational needs (SEN). The NPC report *Making Sense of SEN* (2004) explores the range of issues, as well as government and charitable sector activities relating to SEN in detail. The main findings were:

- 1.8 million children in the UK need help because they may have physical, learning, behavioural or social difficulties.
- Many of these children do not receive adequate support. Provision is heavily fragmented and the government's strongly stated commitment to SEN is not translated into practice.
- Including children with SEN in mainstream schools has created tension in the education system. The charitable sector can play a key role in transferring knowledge from specialist schools to mainstream settings.

- Assessment of children's needs is highly variable and the process of gaining provision from LEAs is often a major battle for parents. The charitable sector plays a key role in supporting parents and improving this process.
- NPC recommends funding organisations and activities that can leverage the state's resources, enhance capacity of schools to deliver education, improve teaching methods for SEN children, and support parents.

This report presents a brief overview of key issues in education for disabled children.

What is the government doing?

Pre-school children

Effective early intervention improves children's health and social and cognitive development. It can also tackle some of the social and physical barriers faced by disabled children.⁵⁴ Delaying intervention results in irretrievable loss of function or ability (e.g. ability to maintain posture), or reduced effectiveness of the intervention (e.g. speech and language therapy).⁴⁷ The government has recognised this in a number of policy initiatives to support all young children (e.g. Sure Start) and those with disabilities (e.g. Children's NSF). In 2003, the DfES and DoH issued a guidance document, 'Together from the start', for professionals working with very young (0–3 years) disabled children. The Early Support Programme is charged with delivering the recommendations laid out in 'Together from the start'. It is developing and evaluating key workers (see Section 3) and family service plans. It provides a range of user-friendly materials for parents and professionals.



Photograph supplied by Circles Network

There are 1,100 special schools in England educating 86,000 pupils.

The ideal situation for children and their parents is to have a choice of high quality mainstream and specialist schools.

LEAs also fund provision of Portage services. Portage is a home-based, early-years educational programme for disabled children or children with development delay. The training supports the development of young children's play, communication and relationships. It enables them to participate in everyday life and be fully included in mainstream society. It emphasises a positive approach and builds on what children can do, so that they and their parents can celebrate achievement. A key principal of Portage is that parents are recognised as the most important people in the care and development of their child.

School age children

The government is responsible for providing education for all school age children. The vast majority of children in England with SEN are educated by the state. Most are educated in mainstream schools, but a number are educated in the almost 1,100 special schools in England (86,000 pupils, or 34% of statemented children).⁵⁵ There are three main types:

- **State maintained** special schools are operated by the state and maintained either by the LEA or by a grant from the DfES.
- **Non-maintained** schools are not-for-profit schools run by charities and funded primarily through pupil fees paid by the LEA (therefore indirectly funded from the public purse). There are 63 non-maintained special schools, which typically provide for children with severe and/or low incidence difficulties.
- **Independent** schools are wholly funded by pupil fees and can be run on a profit-making basis (although most schools for disabled children are not-for-profit). At present, 247 independent schools cater 'wholly or mainly' for children with SEN.⁵⁵

Providing education for children with severe disabilities can be extremely expensive. In one residential school visited by NPC the cost for 48 weeks of education ranged from £95,000–£100,000 per child. Costs for residential special school places are around three times higher than costs for providing for similar needs in a day special school.⁴⁷

The government has recognised the need to improve education for disabled children in an inclusive (mainstream) setting in a number of policy initiatives. In February 2004, it launched a SEN Strategy.⁵⁶ This sets out the approach to supporting education of children with SEN. The Children's NSF is designed to reinforce the SEN strategy and promotes a multi-agency approach by education, health and social services to provide a package of services designed around the child (see Section 3). The Disability Discrimination Act (1995), as amended by the Special Educational Needs and Disability Act (2001), has made it unlawful for schools and LEAs to discriminate against disabled pupils.

The government has funded a range of initiatives in response to this.

- **The Accessibility Planning Project (APP)** promotes effective practice in the development, implementation and evaluation of accessibility strategies in schools. It is funded by the DfES and carried out by the charity **Council for Disabled Children (CDC)** and the Special Educational Needs Joint Initiative on Training (SENJIT) at the University of London.
- **The Reasonable Adjustments Project (RAP)** is producing a practical guide for teachers to help them make reasonable adjustments for their disabled pupils and prospective pupils. The DfES and the Disability Rights Commission commissioned the project, which is being carried out by the charity **Disability Equality in Education**.
- **Schools Access Initiative (SAI)** provides funding to make mainstream schools more accessible to disabled children. It funds: the installation of lifts, stair lifts, ramps and disabled toilets to help physically impaired children; the carpeting and acoustic tiling of classrooms to benefit hearing impaired pupils; and the provision of blinds and paint schemes to benefit visually impaired children. The DfES is giving £100 million to LEAs in 2004–2005 and 2005–2006 for the SAI.
- **Parent Partnership Services** have been introduced in every local authority to support parents of children with SEN. They develop networks between parents, schools and education authorities.

Mainstream versus specialist educational provision

Disabled children must be assessed before their LEA will pay for and provide additional support in a mainstream school or a place in a special school. The assessment may result in the child being issued with a statement of SEN. This details the child's educational (and other) needs and, once finalised, the school to be attended. There are many problems with the statementing process. It can be a long and drawn out struggle between parents and LEAs, involving appeals and legal wrangling. However, getting a statement can be only half of the battle. Parents may have to continue fighting to obtain the services their children are entitled to.

There is a long-running debate regarding the relative merits of mainstream versus specialist education for disabled children and children with SEN. The current trend is for increased inclusion of disabled children in mainstream educational settings. For many disabled children, mainstream education may be the best option. However, educating them in mainstream schools is not without its problems. Children may not get the services that their statement of SEN stipulates. They may be isolated educationally and socially

within the mainstream school or subject to bullying. Some children are prevented from going to their chosen mainstream school because of problems with physical access or the environment.

Some parents and children may feel that even if a mainstream option is available it will not provide the best possible education for them, for social or educational reasons. There are some disabled children, in particular those with complex or additional needs, such as technology-dependent children, for whom education in a special school environment is likely to be the best option.

For such a large group of children with their broad range of needs, there is no clear solution to the question of mainstream versus specialist education. The ideal situation for children and their parents is to have a choice of high quality mainstream and specialist schools; so that they can decide which setting is best for them. There is no evidence relating to the performance of disabled children in mainstream versus specialist schools. This means that an informed choice on the basis of educational performance of disabled children is not possible. Data on (mainstream) school performance is at present limited to threshold measures of the percentage of pupils achieving a minimum level of qualifications. For many disabled children (or children with SEN) these are not attainable; such measures create a perverse incentive for schools either to avoid accepting disabled pupils or to devote limited resources to them. In some specialist schools, such as St Margaret's at The Children's Trust, a child's progress is measured against individual learning objectives developed within its own curriculum.

What is the charitable sector doing?

Charities play a key role in the development and delivery of services for pre-school disabled children. They support parents by guiding them through the complex and often conflicting information given by professionals.

Scope has worked with parents to develop guidelines to help professionals deliver news of a child's special needs to parents. The government has adopted the 'Right from the start' template as part of its 'Together from the start' guidance and the Children's NSF.

The National Deaf Children's Society produced a comprehensive guide on childhood deafness, funded by the DfES. It gives unbiased information on the merits of learning sign language or learning to lip read — parents are often given contradictory information about this subject.

The **National Autistic Society (NAS)** developed early intervention advice through the Early Bird Scheme, a course designed to give parents more control over their lives by providing an understanding of autism and its impact on their child. It enables parents to help children early, thus avoiding challenging behaviour later. The NAS retains ownership of the scheme to ensure

“Coming to Atlantic College means that I get some freedom and a rest from my mum ... I get to meet new friends with the same problems I have.”

Disabled young person ³⁶

quality control and franchises it out to LEAs. It is funded mainly by LEAs, but occasionally by parents. It involves ten weekly sessions, followed by at-home support. Barnardo's delivers the Early Bird Scheme in some areas.

Kids, The Children's Society and other voluntary organisations deliver Portage services on a contract basis for local authorities. Delivery of Portage at home is generally funded on a fee per service or contract basis with local authorities. However, there are often long waiting lists or rationing of services; authorities often do not cover the full costs of provision. Donations given to organisations delivering Portage are unlikely to purchase more Portage services for children, but instead may be used to top-up local authorities' contributions or pay management costs. It may be used to share best practice between Portage services operating in different areas. This does not mean that donors and funders should not give money to charities that deliver Portage services, but they should not think that these funds will be used to purchase additional services (this is also true for short breaks, see Section 2).

Mencap is leading a feasibility study commissioned by the DfES. This considers a national centre for early intervention that could provide information and publish research on what works, develop courses and training and publish key research messages.

Funding school-age education of disabled children is the responsibility of the statutory sector. However, the charitable sector plays a number of important roles from curriculum development to service delivery.

Statutory sources should fully fund individual places for disabled children at schools. However, there are a number of instances where charitable income can improve or expand the education services on offer for disabled children. Many special schools run by charities or trusts provide services above and beyond those that could reasonably be funded by LEAs. They require income to fund these additional services. Schools may also find it difficult to expand services or capacity. Therefore, voluntary income is important for capital expansion (buildings) and also to pioneer new services.

The National Autistic Society provides early intervention advice through the Early Bird Scheme.

Special schools run by charities play a key role in developing the curriculum and learning materials for disabled children.

Special schools run by charities often play a key role in developing the curriculum or learning materials for disabled children. For example, the **National Autistic Society** runs six specialist schools and ensures that lessons learnt on how best to educate autistic children are transferred to mainstream schools.

The voluntary sector is also working to support disabled children in mainstream educational settings. For example the **National Blind Children's Society** has developed national curriculum materials and revision guides for partially sighted children. **The National Deaf Children's Society** has developed a 'deaf friendly' pledge to help schools make provision more accessible for children with impaired hearing. They have also carried out work on bullying in schools; it wants to expand this and focus on disabled children.

Contact a Family advises on a wide range of educational issues; they also provide vital signposting to local Parent Partnership Services.

The **Council for Disabled Children** works with LEAs to improve education services for disabled children. It also houses the **Special Educational Consortium (SEC)** and the **National Parent Partnership Network (NPPN)**. SEC protects and promotes the interests of children with SEN and disabilities when there are proposals for changes in legislation, regulations or guidance. NPPN is the umbrella group for local Parent Partnership Services.

What are the outcomes of improving education for disabled children?

The main result of charitable activity in the education of disabled children is an improvement in the quality of education provided. Charities can ensure that the curriculum is more accessible and appropriate for disabled children. This allows children to achieve their potential. Charities also provide high quality specialist education places at independent or non-maintained schools. Even where LEAs fund individual child placements, charities often top up to ensure additional activities or facilities are available. This results in improved educational outcomes for disabled children. Better education leads to increased social inclusion of disabled people into the workplace and community.

Section summary: children

Disabled children have the same needs as their non-disabled peers: to have fun, make friends, play and go on holiday. However, many barriers prevent them from doing these things. Lack of accessible leisure facilities that can cope with additional needs, means there are fewer social opportunities for disabled children. Being in a school far away from home makes it difficult for them to see friends. Public attitudes make disabled children feel uncomfortable when they do go out. Financial constraints and poor transport also limit opportunities for holidays and outings. Many disabled children do not get the equipment, therapy or communication aids they require. This can slow their development and limit their capacity to participate in their school, home and social lives. Disabled children often have a poor experience of education and parents have to fight for services.

Recent legislation, such as the DDA, should improve access to transport and leisure facilities for disabled children. Some additional statutory funding is earmarked for improving inclusive leisure services. The FF provides holiday grants, but often this money is needed for basic items, such as washing machines, so families do not get a holiday. Efforts are being made to improve equipment services and 'join up' the different local authority departments responsible for equipment and therapy services. The government also has a strategy to improve education for children with special needs. In spite of these efforts, the pace of change is slow and statutory services are failing to meet the needs of disabled children.

There is a clear role for charities to push for an accelerated pace of change, lobbying with and on behalf of disabled children. They can also develop and share best practice in meeting the needs of disabled children. Simple things are extremely important to children. Charities recognise this. For example, they support disabled children to make friends, provide opportunities for them to interact with non-disabled peers, and build confidence by letting them experience new and exciting places and activities. Supporting charities to do these things will help ensure that disabled children, now and in future, are allowed, simply, to be children.

There is a clear role for charities to push for an accelerated pace of change, lobbying with and on behalf of disabled children.

This section sets out the financial, practical and emotional burdens of raising a disabled child. The government could do more to relieve these burdens and, particularly to lift families out of poverty. While not a truism, it is usually the case that a family with a disabled child is poor. Increased national and local advocacy is needed to accelerate government action.

Raising a disabled child has a profound impact on a family. For some, the experience brings them closer together, but it can also lead to relationship, financial, physical and psychological strains. A Contact a Family survey of over 2,000 parents with disabled children found that 76% suffered stress or depression, 72% experienced tiredness or lack of sleep, 51% had financial difficulties, 32% had problems at work and 22% had housing problems.⁵⁷ This section explores these issues and what the government and the charitable sectors are doing to help.

Families with disabled children

Disability cuts across gender, ethnicity, geography and socio-economic class.* The families of disabled children are extremely varied in terms of demographics.¹ What links them together is the life-changing event of having a child diagnosed with an impairment. Although family experiences will be highly individual, there are some common threads. It is important to note that while all families have similar needs in varying degrees, some groups have greater needs overall.

Single parents are one such group. Single parent families are more common when there is a disabled child, indicating the strain on marriage from caring for a disabled child. In a representative sample of 7,070 British families in 2002, 31% supporting a disabled child were lone parent families.¹¹ This compares to 24% among other families. Put another way, 20% of all lone parent families are supporting a disabled child compared with 14% of couple families.¹¹ A different sample of over 5,000 British low-income families in 1999, found that an

31% of families supporting a disabled child are lone parent families.

astonishing one third of lone parents had at least one child with a long term illness or disability.⁶⁰ Contact a Family found that 44% of parents felt that having a disabled child had caused relationship problems. An additional 9% said that having a disabled child had led directly to separation. The survey found that 17% of respondents were bringing up a child on their own.⁵⁷

'Having a child with disabilities is shattering, it changes your life. My husband and I split up last year. It gets to the point that it is too painful to talk about your child so you stop talking to each other completely.' Parent⁶¹

Having more than one disabled child places additional strain on the family. An analysis of the Family Fund (FF) database in 1997 found that around 17,000 families in the UK have more than one disabled child and 7,500 of these have two or more children with severe impairments.⁶² Barnardo's estimates that 10% of families with disabled children care for more than one disabled child.³⁹ These families are more likely to be single parent families, less likely to be in work, less likely to be in their own homes and more likely to be dependent on income support.⁶³ Additionally, in families with two or more disabled children, the whole family is involved in providing care and support, including disabled children and their non-disabled siblings. The whole family is isolated and has a restricted life.⁶² The needs of these children and their families vary from those of households with one disabled child.

'They [families] shouldn't have to fight for everything – but they have to. And it's harder to battle for two than it is for one.' Community Nurse⁶²

Another group of families with additional needs are those where one or both of the parents is disabled. Disabled parents need extra support to bring up a child. There is little information on the number of such families or the type of additional support they require. What is known is that children in families with both a disabled adult and a disabled child are particularly at risk of poverty. Roughly two-thirds of this group are in the bottom two quintiles of income distribution.⁶⁴

“We are a disabled family, we don't just have a disabled child – it impacts on every single aspect of our lives.” Parent⁵⁸

* Although the Health Survey for England in 2002 found that children from lower income households are more likely to report long standing illness or disability this is a two-way relationship (as discussed in Section 1).⁵⁹ Lower birth weights in lower-income households may lead to an increased incidence of disability. However, child disability invariably leads to lower income and additional expenditure.

¹ Our use of the term 'family' includes (unpaid) carers and siblings of disabled children.

Black and Minority Ethnic families with disabled children have a high level of unmet need.

Black and Minority Ethnic (BME) families also have a high level of unmet need. Parents in this group report language, communication and information barriers to accessing services. Services may be inappropriate because of insensitivity to religious and cultural needs, such as diet and preference for care in the home, rather than outside of it.^{6, 65} This results in a lower take-up of services and benefits. The Audit Commission confirmed that this group were disadvantaged in comparison with their peers.⁶

'The main problem faced as a Muslim was that I was expected to adapt to services and cultural needs were not dealt with... Often I felt inferior because we didn't do things their way.'

Parent⁶⁵

Family needs

Financial support

What is the situation?

Extra costs

The Centre for Research in Social Policy found that it cost an average of £8,300* a year to bring up a severely disabled child. The minimum essential budget from birth to age 17 is approximately £143,000† with the largest proportion being spent on transport. This is at least three times more than the amount required to raise a child without a disability.⁶⁶ The additional cost includes expenditure on trips to the hospital, heating, housing, clothing, bedding, laundry, equipment and housing adaptations. A recent pilot study on the costs of autism concluded that families incur additional expenditure of at least £66 per week.**⁶⁷ Of this, 40% is spent on extra help, 22% on special food, clothes, damages and extra laundry, and, 14% on additional transport. The remainder goes on special activities, therapy, education, legal costs and extra costs for siblings. Another recent study reported that families require an extra £105 per week over and above their current incomes to meet their child's needs satisfactorily.⁶⁸

'It's all the little things, the extra clothes, sheets, even food that you're buying every week and you don't realise what it costs or rather it would scare you if you sat down and worked it out, so you don't. Every now and again I'll think I'll get myself some new clothes because mine are almost in holes, but I come home with things for Erin, because she needs it more than me. And just when you think that you might be getting straight, it all falls apart, she'll have a bad patch and maybe she'll need a new bed or she's back in hospital and that costs. The thing you have to realise is that everything like this is a disaster for us.'

Parent⁶⁶

Although the FF is unable to provide grants for services or items which should be provided by the government (such as wheelchairs and short break services) a review of their disbursements is indicative of some of the needs of families with disabled children. In 2003–2004, the fund distributed 103,305 items to 41,634 families. The breakdown of items is shown in Figure 8.¹⁵ In one year alone, it disbursed funds for 14,382 washing machines! One study found that parents did 14 washes a week for a child with a severe disability, compared with only two for non-disabled children.⁶⁶

'When my son was poorly, he wet the bed five times and that was five pairs of pyjamas and five sets of bedding just in one night.'

Parent⁶⁶

It costs three times more to raise a disabled child than to raise a non-disabled child.

Figure 7: The financial equation of families with a disabled child

Extra costs	+	Inability to work	=	Poverty	+	Debt
3 times the cost of raising a non-disabled child		Only 16% of mothers in full- or part-time employment		55% of families with a disabled child live in poverty		84% of families with a disabled child are in debt

* This has been calculated by adjusting the 1997 figure of £7,355 by the consumers' expenditure deflator to arrive at the 2004 figure of £8,333.

† This has been calculated by adjusting the 1997 figure of £125,000 by the consumers' expenditure deflator to arrive at the 2004 figure of £141,625.

** This study involved 15 parents with 17 children. It used a diary survey over 14 days to estimate the parental time spent and costs incurred.

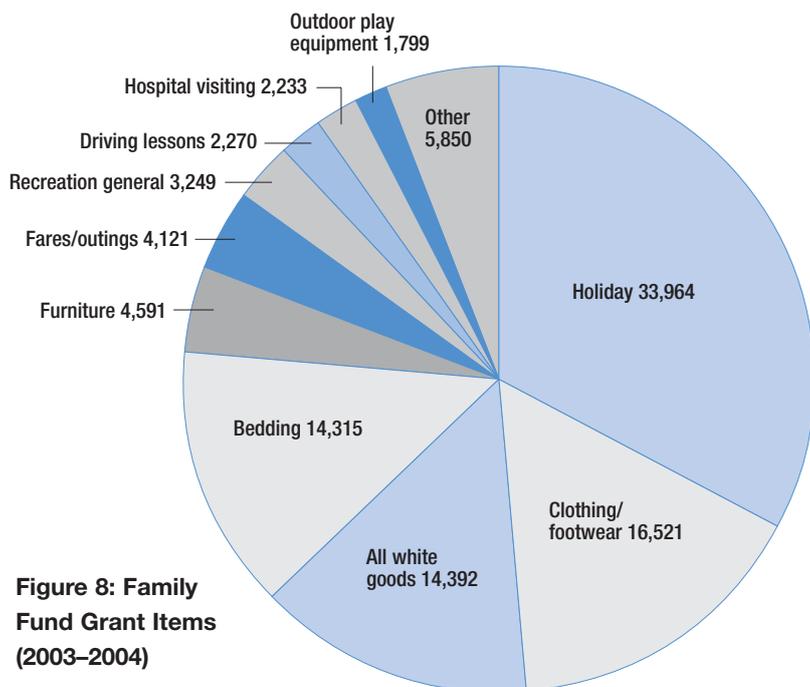


Figure 8: Family Fund Grant Items (2003–2004)

Over 80% of disabled children’s mothers are unemployed.

Only one study has attempted to measure the economic impact of disability on society. This study considered the costs for service use (including hospital, other health and social services, living support, special education, day care provision, and medication), time and productivity, and family expenses of an autistic person. It concluded that the overall cost of autism in the UK exceeds £1 billion per year (based on an assumed prevalence of five cases per 10,000). The lifetime costs for a person with autism were found to exceed £2.4 million. The costs of living support and day activities account for almost 90% of this cost.⁶⁹ Legal compensation awards provide an alternative financial estimate of the cost of disability (see Box 8).

Inability to work

On top of the additional expenditure described above, most carers of disabled children are unable to work because of intensive care requirements and the lack of, or prohibitive cost of, appropriate childcare. Families supporting a disabled child are 2.5 times more likely to have no parent working for more than 16 hours per week (32%, compared with 16% of other families).¹¹ Analysis of 2002 FF data shows that only 16% of disabled children’s mothers work full or part-time¹⁵, compared with 61% of all mothers (from the General Household Survey 2002).²¹ The inability to work is compounded by the higher rate of lone parents among families with a disabled child. Analysis of single parent applicants to the FF, found that 82.7% were unemployed. This compares to 2001 Census estimates that 51.3% of all single parents are not employed.²¹ In fact, 35% of non-working single parents have a disabled child.⁶⁰

‘You can’t work when you’ve got a child like ours, it’s just not possible. I tried and you always need time off when they’re ill and they’re ill more than normal children, then you’ve got all the appointments as well. But the killer is the holidays, what do you do with them then?’

Parent ⁶⁶

‘There is added stress when you have to fight for your rights. If services were easy to get we wouldn’t have to type out loads of letters, fill in forms. Try doing this and keeping a full-time job going, I feel I have to stay at home to fight for our rights.’

Parent ⁷²

The ability to work is further restricted in families with two or more disabled children. One small study found that in only one third of these families was either parent employed, although virtually all of the parents said they would like to work. Loss of benefits often means low-paid work is not financially worthwhile. In some families the fathers had given up work to help provide care.⁶²

Box 8: £3.9 million lifelong care costs

Two recent high court cases have awarded over £3.8 million each in compensation to individuals who became brain-damaged due to hospital negligence.

In the first case, Lewis Prosser, now aged seven and with severe cerebral palsy, was awarded £3.85 million in damages because of failings in the care of his mother’s pregnancy, labour and his birth. According to the Prossers’ solicitor, the damages award was mostly made up of the cost of essential lifelong care for Lewis.⁷⁰

The second case awarded Claire McEvoy £3.9 million. She is now aged 20 and has impaired intellectual and communication skills and mobility problems. She contracted listeria on a post-natal ward which led to hydrocephalus (water on the brain) which went un-diagnosed for two years.⁷¹

At least 55% of families with a disabled child live in poverty.

84% of families with disabled children are in debt. This compares to 47% of all households.

The level of benefit needs to increase by 20 – 50% to meet the additional costs of raising a disabled child.

Poverty

The additional expenditure combined with lower income-earning capacity of families with a disabled child results in poverty for many. Based on an analysis of government data, 55% of families with a disabled child were living in, or on the margins of, poverty in 1985.¹¹² Households with disabled children were four times more likely to be living in poverty. A more recent study found that families with a disabled child were more than twice as likely than other families to be unable to afford five or more everyday items.¹¹ Many experts consider even these startling figures to be underestimates.

Income figures do not give a full picture of poverty levels because they do not take into account additional expenditure. However, they do shed some light on the earning capacity of households with disabled children. Recent Department for Work and Pensions (DWP) figures show that there are almost three times as many families with disabled children in the lowest income quintile as in the top quintile.⁶⁴ Using a standard income measure of poverty (60% below the median income level after housing costs), 29% of people with one or more disabled children in the household live in poverty, compared with 21% in households with no disabled children.⁶⁴

The Government's Social Exclusion Unit states: *'The single most important feature of the experience of families with disabled children remains poverty. Greater childcare costs and lower parental incomes are strongly associated with childhood disability'⁷³ [...] Of adults with a disability, 29% live in a low-income household, compared with 22% of all individuals. For households containing either a disabled adult or child(ren), this rises to 43%.'*⁷⁴

Debt

Although there is evidence of higher expenditure, lower incomes and higher likelihood of poverty for families with disabled children, data about the extent and nature of indebtedness among these families has only recently been collected. In a study commissioned by the Department of Trade and Industry (DTI) in 2002, only 16% of families with disabled children said that they had no debt. This compared to 53% of all households reporting no debts.⁷⁵ Families with disabled children were four times more likely to owe in excess of £10,000 (16% as compared to 4%).⁷⁵ In another recent survey of 1,843 families, only

6% reported they were 'comfortably off' with 93% reporting some form of financial difficulty.⁷⁶ Families from BME groups were slightly more likely to be in financial difficulty. The survey also found that 55% of families had not sought any formal advice about their debt. Of those who had, the majority agreed that it was hard to get advice.⁷⁶

Such high levels of debt, with no foreseeable end, increase levels of stress, mental health problems, relationship breakdowns and fear at facing an uncertain future. Families with disabled children are highly unlikely to break out of debt, unless their incomes increase significantly.

'You think it gets easier as they get older but it doesn't, the money still isn't there and the debts are bigger. I don't worry about the bills now, that's the only difference. What are they going to do to me, put me in prison? Great, a room to myself and a night's sleep. That would be the first in nearly 15 years.' Parent⁶⁶

'We live with high debts as without this we wouldn't have furniture or days out with her. I owe £6,000 on my credit card, which I have for such a long time now, and I have a bank loan of £10,000, which bought all our furniture, carpets, clothes, toys and paid for the move.' Parent⁶⁶

What is the government doing?

If the government is to reach its goal of halving child poverty by 2010 and eradicating it by 2020, it must urgently target families with disabled children.^{**} The current government has extended financial benefits for families, improved the rights to flexible work and increased childcare provision — but none of these measures has been targeted specifically at this group. Much more remains to be done for families of disabled children before the goals are realised.

Benefits

There are a number of tax credits, benefits and grant programmes that provide financial assistance to disabled children and their families. These are summarised in Table 4.

The benefits system acknowledges that disabled people and their families incur additional costs. However, the level of benefit in no way meets the additional costs. A 1998 study on the cost of caring concludes that benefits would need to be increased by 20–50% depending on the child's age and type of impairment.⁶⁶ Similarly, the charity Disability Alliance estimates levels would need to increase by 30–50% to raise disabled children out of poverty.²¹ The nominal rates of DLA have been increasing at a rate of

* This study used the 'consensual' or 'perceived deprivation' approach to measuring poverty. Thus, it defined poverty from the standpoint of the public's perception of minimum need. Families suffering the enforced lack of three 'necessities' or more were considered to be 'in poverty'.

¹ 1,007 of the families included in the survey were drawn from the FF database. As the FF only supports families with incomes below £23,500, this introduces downward bias into the survey and results should be interpreted with caution.

** NPC analysis of DWP 2002/2003 data⁶⁴ suggests that as many as 14% of all children living in poverty live in a household with one or more disabled child.

Table 4: Main benefits available to disabled children and their families

Category	Benefit	Description	Level*
Disabled Child	Child Benefit	Paid by Inland Revenue to everyone responsible for a child from birth up until 16 (19 if they stay in full-time education). Not affected by income or savings.	£16.50 per week for eldest child. £11.05 per week for every other child.
	Child Tax Credit (CTC)	Paid by Inland Revenue to people with children subject to household income but not dependent on parent's employment status. Made up of a family element and a child element. Weekly supplement if child gets DLA at any rate.	Up to £42.49 per week for each disabled child. A further £17.08 for each severely disabled child.
	Working Tax Credit (WTC)	Paid by Inland Revenue to the person who is working 16 hours or more a week depending on annual income and circumstances. Childcare element of up to 80% of childcare costs as long as the care is provided by an approved provider.	Childcare maximum of £175 per week for one child and £300 per week for two or more children.
	Child Trust Fund (CTF)	A savings and investment account for every child born since September 2002 which can be accessed when child reaches 18. Amount contributed by government doubled for low income families. Disabled CTF proposed but not yet available.	Government contributes £250 at birth. Others can contribute a total of £1,200 per annum.
	Disability Living Allowance (DLA)	Introduced in April 1992, DLA is a non-contributory, non-income related, non-taxable weekly benefit paid by the DWP for disabled people, including children. Two components: Care component: 3 different rates — lower (for extra help or supervision of at least an hour a day), middle (extra help or supervision frequently throughout day or night) and higher (extra help or supervision during the day and night). Claimed from 3 months or birth if child is terminally ill. Mobility component: 2 different rates — lower (can walk but needs extra supervision) and higher (can't walk or is physically hard for them). Higher rate claimed from 3 years and lower rate from 5 years.	Lower: £15.55 Middle: £39.35 Higher: £58.80 Lower: £15.55 Higher: £41.05
	Help getting around	Freedom pass for child to travel free on public transport. Blue Badge to park closer to facilities if child is over 2 years. Motability Scheme helps to hire or buy a car if child is on higher rate of DLA mobility component. Exemption from road tax if child is on higher rate of DLA mobility component.	

If the government is to reach its goal of halving child poverty by 2010 and eradicating it by 2020, it must urgently target families with disabled children.

Table 4: Continued

Category	Benefit	Description	Level*
Carer	Carers Allowance (CA)	Taxable weekly benefit for informal carers over 16 years of age who spend at least 35 hours per week caring for someone receiving DLA, earn less than £79 per week and do not study for more than 21 hours per week.	£44.35 (plus £26.50 for dependant spouse)
Other	Disability Facilities Grant (DFG)	Means-tested grant towards the cost of providing adaptations and facilities to enable a disabled person to continue to live in their home. An assessment of needs is made, usually by an occupational therapist from social services.	Maximum per person of £25,000
	Social Fund	Grants given to help people on low income with specific payments including: <ul style="list-style-type: none"> • Maternity Grants • Funeral Payments • Cold Weather Payments • Winter Fuel Payments • Crisis Loans • Budgeting Loans • Community Care Grants (often awarded to families with disabled children) 	Various
	Family Fund (FF)	Means-tested small grants for families of disabled or seriously ill children under 16 years. In 2003/2004 the Family Fund distributed £27.1 million to 41,634 families. All funding comes from the government and cannot be used to fund items which should be provided by statutory authorities.	Average grant: £625
	Family Welfare Association (FWA)	Administers funds from over 70 trusts that have very diverse eligibility criteria. Funds items such as clothing, fuel bills, and household needs, e.g. beds and cookers. Applications must be made by a social worker. FWA is unable to help with anything already provided by the statutory authorities.	Various
	Low Income benefits	Families may be entitled to a number of benefits including Income Support (IS), income-based Jobseeker's Allowance (JSA), Pension Credit, Housing Benefit (HB) and Council Tax Benefit (CTB). A carer premium is available on most of these if CA is claimed.	Various

* These levels are a guide only and can be affected by a number of factors including any residential care of the child, income levels and other benefits received.

approximately 2.5% since 1992. This is barely in line with inflation.* Significantly, the higher rate of DLA mobility component was extended to three and four year olds in 2001, but many organisations are still campaigning for higher levels of DLA.

The benefit system fails to take into account the cumulative costs of having more than one disabled child. For example, where two children in one family both fall outside the criteria for the care component of the DLA, the family will receive no award, despite the overall burden of care.

A further problem is that many families do not receive the maximum benefits available because of the difficulty in finding out about, and claiming, benefits. As Table 4 illustrates, the number of benefits, agencies that administer them, eligibility criteria and claim processes are complex (see Box 9). The form for claiming DLA has 47 pages and many people find it hard to complete, even with assistance. A Commons Public Accounts Committee report found an astonishing half of all decisions on DLA and attendance allowance contained errors.⁷⁸

One qualitative study found that the stigma and shame of applying for benefits were also major obstacles to claiming.⁷⁹ Even when families manage to secure DLA, the fact that it is repeatedly downrated or withdrawn (after the two to five year period for which it is granted), generates considerable income fluctuations and high levels of stress and ill health.⁷⁹

In 1998, the government estimated that only 30–50% eligible people were taking-up the DLA care component; for DLA mobility component the take-up was 50–70%.⁸¹ In August 2004, only 271,000 children under the age of 16 were receiving some level of DLA.⁷⁷ This represents a mere 39% of all disabled children. Take-up has been increasing — but not at a high enough rate. In the five years to February 2004, the number of children receiving DLA increased by 30%.⁸² Of families applying to the FF for grants, 82% were receiving DLA and a further 12% had pending applications. The majority (71%) were receiving no DLA mobility component help.¹⁵ Data from the FF and the charitable sector indicates a lower rate of take-up of disability allowances among ethnic minority families.^{21, 65}

'I wish the government would provide us all with one idiot-proof booklet, the easy guide to what you're entitled to.' Parent⁵⁸

The government has supported a number of activities to raise awareness of DLA and increase take-up. However, as the Social Exclusion Unit states: 'A number of positive changes to benefits/tax credits have occurred since 1999. However, improving the take-up of benefits, especially Disability Living Allowance, remains a challenge.'⁷³ A national awareness campaign is still required. DWP is at present improving the claims process for disability benefits and developing a new DLA form appropriate for carers of disabled children. It is hoped that a more personal and responsive service will remove barriers and encourage people to claim. DWP has commenced consultation with groups representing disabled children and will be testing the new forms in 2005.

In April 2004, 103,000 families were benefiting from the additional support provided by the Child Tax Credit (CTC) for disabled children. This is more than three times the number of families who benefited from the previous disabled child credits.⁸² Entitlement to the disabled child elements of CTC is based on DLA eligibility. Contact a Family has received government funding to increase take-up of the CTC and Working Tax Credit (WTC). The FF also signposts eligible parents to the relevant tax credits.

Removing barriers to employment

*'The government's role is to support families and ensure that they have meaningful choices about how they live their lives. This means ensuring that parents are able to spend time with their children, particularly during the first year of life, enabling flexible working, providing joined-up support and guidance services and increasing availability of high quality, affordable, flexible childcare provision. It also means making sure the poorest and most disadvantaged children and families have access to the support they need.'*⁸³

Box 9: The case of Ali Abbas

Ali Abbas, the 14 year old Iraqi orphan who lost both arms in the Iraq War in April 2003, applied as a British resident to DWP for Disability Living Allowance in October 2004. Although pictures of him crying in a Baghdad hospital were shown around the world, he received a letter in March 2005 saying no backdated disability payments would be provided. He could only receive benefits from March 21, 2005 because conditions set by the DWP on his disability had not been satisfied for the prior period.

Zafar Khan, chairman of the Limbless Association, commented: 'It's appalling the way he's been treated. I am wondering how many other people like Ali are suffering through this incompetence and negligence.' Scope's campaign officer added that the case was 'all too typical of the kind of red tape facing disabled people when they try to claim what is their statutory right'.⁸⁰

Following exposure of his case in the media, Ali was given a formal government apology and backdated payments.

Only 39% of disabled children are claiming Disability Living Allowance.

* NPC analysis of DWP August 2004 DLA quarterly data.⁷⁷

The Employment Act (2002) has increased parental rights at work. Parents with a disabled child under 18 years now have the right to apply for flexible working arrangements. Employers have a duty to consider these requests seriously and refuse only when there is a clear business reason. A recent survey of over 900 parents by Contact a Family found that there is still a considerable lack of awareness among parents about their new rights.⁷² Parents who have successfully used their new rights to arrange more flexible work reported major benefits.

Photograph supplied by Choices



Only 10% of childminders offer services for disabled children.

Even with more flexible work arrangements, many parents are prevented from working because of a lack of appropriate, affordable childcare. Half of the parents surveyed by Contact a Family who wanted to work, reported that the lack of suitable childcare was the major barrier.⁷² The government is responding and the National Childcare Strategy (1998) signalled an increase in government spending on childcare. More recently, a ten year strategy for childcare has been articulated, as has a vision for disabled childcare (see Box 10).⁸³ Since 1997, more than 553,000 new childcare places have been created, benefiting just over one million children. The Working Tax Credit, which includes an element of childcare tax credit, has also helped parents (see Table 4).

Although these general measures are welcome, research by the Daycare Trust in 2001 found that childcare for disabled children was extremely limited. This was largely because of inaccessible buildings and a lack of expertise.⁸⁴ A recent

National Audit Office report found that the situation had improved, but disabled children still get proportionately less childcare than other groups. The difference was particularly marked in childminder provision: only 10% of childminders offer services for disabled children. School-based provision is more widely available, but is limited in terms of numbers.⁸⁵ Furthermore, although 5% of British children are disabled, only 2% of the planned childcare places announced by the government in July 2004 were reserved for 'vulnerable' children, disabled and non-disabled included.⁸⁶ It is imperative that implementation of the ten year strategy explicitly considers the needs of disabled children.

Direct Payments

Introduced in 1996, Direct Payments allow disabled people to choose between direct services (such as help from social services) or the value of the service as a cash payment. The Carers and Disabled Children Act (2000) made Direct Payments available to 16 and 17 year olds, carers and people with parental responsibility for disabled children. In April 2003, it became compulsory for local authorities to offer Direct Payments to all individuals entitled to social services who meet the eligibility criteria. Direct Payments transfer control to the disabled person or their parent/carer, and increase choice.

To be eligible for Direct Payments, social services must have already assessed the disabled person and given them a funded care package. Direct Payments are therefore largely dependent on the adequacy of an assessment. Furthermore, eligibility and accessibility of Direct Payments varies widely between authorities, as does availability of services.⁸⁷ Direct Payments cannot be used to purchase health services or services from local authorities; in areas where most services are provided in-house, choice is restricted. In fact, the Council for Disabled Children (CDC) found that where local councils had a wide range of good direct services, parents were less likely to opt for Direct Payments.⁸⁸

A Scope study of 31 people getting Direct Payments found that all of them used the money to recruit personal assistants.⁸⁷ Many local authorities did not allow the money to be used on equipment and adaptations, or had no policy or support on expenditure in other areas. The notional hourly pay rates for personal assistants used to determine levels of Direct Payment vary greatly.⁸⁷ They can also be inadequate. In one conversation with a father of two disabled children, NPC learnt that he was offered a Direct Payment of £50 per night; while the service provided by the local authority cost approximately £30 per hour.

Box 10: The government's vision of childcare

'All families with a disabled child should receive childcare provision which is sustainable, high quality, flexible, affordable and accessible — in other words, implementation of the 10-year Strategy for Childcare should include disabled children and their families on equal terms with non-disabled children and their families.'

'As part of the 10-year strategy for childcare, the Sure Start Unit should ensure, by 2015, all families with a disabled child under five years, can access high quality, flexible childcare.'

Prime Minister's Strategy Unit²⁹

In September 2003, Commission for Social Care Inspection (CSCI) figures showed that only 875 parents of disabled children and 125 disabled young people (aged 16-17 years) were receiving Direct Payments. Although this is roughly four times the number of the previous year, it is still less than 1% of disabled children.⁸⁶

A recent CSCI report found that the main barriers to take-up are a lack of clear information, low staff awareness, restrictive or patronising attitudes about the capabilities of potential recipients, a reluctance to devolve power, inadequate support services, over-bureaucratic paperwork and difficulties with recruitment of personal assistants.⁸⁹ The Scope study found that most parents had difficulty in getting information on Direct Payments from local authorities. Respondents stated that more training was required in employment law, producing contracts and job descriptions, and the disciplinary process.⁸⁷

The government has urged councils to promote Direct Payments. It has encouraged take-up by supporting the work of the National Centre for Independent Living. The Department of Health (DoH) set up the Direct Payments Development Fund to support the role of charities in expanding use of Direct Payments. A new Direct Payments guide was published in September 2003. Since 2002–2003, the take-up of Direct Payments has featured in the indicators against which the performance of social services is rated. The government has recently introduced the concept of ‘individualised budgets’ for disabled people and families with disabled children. These budgets build on Direct Payments and could encompass housing, transport, equipment, childcare and support services (akin to the Austrian model described in Box 11). The government recommends that these are in place by 2012.²⁹ At present, take-up of Direct Payments remains low and individualised budgets are at concept stage. There is much to be done before a significant number of disabled children and their families benefit.

What is the charitable sector doing?

It is the responsibility of the government to alleviate poverty and charities should not step in where the state has a legal responsibility. However, charities can help by providing information and advice and, sometimes, topping-up grants. Charities play an important role in lobbying the government to change policies, programmes, benefit levels and legislation.

Contact a Family informs families with disabled children about the benefits they are entitled to and how to access them. It also provides information on their rights to flexible work and guidance on how to approach employers.

Box 11: International best practice – Direct Payments in Austria

In Austria, the state provides a direct cash benefit to all 300,000 disabled people and their families. The amount is non-taxable and not means-tested. It has seven rates depending on the hours of care needed per week, ranging from €145 (£98) to €1,532 (£1035) per month, with an average of €405 (£274). After assessment there is no monitoring of the spending; yet no evidence of bad practice has emerged. Information and help from a team of professionals (including doctors, psychologists, and psychiatrists) is provided by mobile support units in six major towns.⁹⁰

Local **Citizens Advice Bureaux, welfare rights centres** and **parents advice centres** provide information on benefits and how to claim them. Citizens Advice Bureaux also advise on debt. Local organisations working with disabled children and their families, such as **KIDS** and **National Deaf Children’s Society**, often help fill out forms and deal with the administrative process of accessing benefits.

The **Daycare Trust** is a charity which aims to promote high-quality affordable childcare for all. They are active campaigners and provide information for parents, childcare providers, employers, trade unions, local authorities and policy-makers. They recently completed research on childcare for disabled children.

The **Action for Carers and Employment (ACE)** project is led by **Carers UK** and funded by the European Social Fund Community Initiative until May 2005. The overall objective is to raise awareness of carers as a distinct group within the labour market and to work with various agencies to research and overcome barriers to employment. Five local projects advise and train parents on returning to work. The **Nigel Clare Network Trust** offers practical support for combining work and caring responsibilities and **Working Families’ ‘Waving Not Drowning’** project is a network for working parents of disabled children.

Disability Law Service (DLS) is a charity that helps disabled people access the benefits and services they are entitled to (see Box 12). Local **law centres** also assist with legal entitlement issues, although they do not specialise in disability.

Only 875 parents of disabled children and 125 disabled young people are receiving Direct Payments.

Box 12: Disability Law Service case example

DLS represented a young autistic boy in a case concerning the payment of the higher rate of the mobility component of the DLA. The Social Security Commissioner had decided that since his IQ was greater than 55 he could not be held to have a severe mental impairment. DLS argued that IQ tests were not a useful measure of intelligence for people with autism and that a person’s ability to interact with others (social intelligence) should be taken into account. In a landmark ruling, the Court of Appeal agreed. This decision will mean an increase in weekly income of over £23 for many autistic people.⁹¹

The **Council for Disabled Children** has provided guidance to local authorities around the country on setting up Direct Payment schemes. It continues to disseminate best practice in this area and to campaign for increased uptake. The **National Centre for Independent Living** is also actively working to increase the take-up of Direct Payments. Local **Mencap** organisations assist people with learning difficulties to access Direct Payments.

Family Welfare Association is a national charity that provides means-tested grants to families in need (see Table 4). The charity **React** provides financial grants to families with children who have a life-limiting illness or disability.

The **Family Fund (FF)** is lobbying the government to triple the rate of child benefit for families with disabled children and to launch a benefits take-up campaign for these families. It is also urging the government to extend its grants programme to families with incomes above £23,000 and families with children over the age of 15. The **End Child Poverty** campaign and **Council for Disabled Children** are campaigning for a number of measures that will go some way to reducing child poverty among disabled children. The **Disability Alliance** is monitoring take-up of existing benefits and is part of the End Child Poverty and Homes Fit for Children campaigns. **Barnardo's** is campaigning for a national benefits take-up campaign. Additionally,

a coalition of charities, including **Mencap**, **Barnardos**, **NCH** and the **Muscular Dystrophy Campaign**, is campaigning for changes to the Disabilities Facility Grant. They want to abolish the means test, streamline the application process to reduce waiting times, and increase the current limit (some families have to pay more than £50,000 towards the cost of adaptations).

Given the acute level of need, the best form of immediate help would be to give money directly to the families of disabled children. They can be easily identified; they are either in receipt of DLA or FF grants. However, the mechanism for such payments of charitable money does not yet exist. The FF has the infrastructure in place and believes that it would be able to administer a fund providing unrestricted small grants to families.

What are the outcomes of financial assistance?

Adequate financial assistance enables families with disabled children to purchase the additional items and services needed as a result of impairment, without forcing them to borrow or cut out necessities. With financial help, families with disabled children can be lifted out of poverty.

Direct Payments and individualised budgets go further by 'enabling' families with disabled children and providing them with choice and control over which services they receive and when.

“By employing a personal assistant it means I do not have to be so dependent on my family and I can see my friends when I want to.”

Young person⁸⁸

Adequate financial assistance enables families with disabled children to purchase the additional items and services needed as a result of impairment.



Photograph supplied by Circles Network

'Direct Payments have been brilliant. The children have been able to live a normal life and my husband has not had to give up his job.'
Parent⁸⁹

'We can now have a break, this is for the first time in 17 years.'
Parent⁸⁹

Where parents know about, and have used, the new rights to request flexible working hours, their ability to cope has increased significantly. They claim to be less worried, pressured or stressed.⁷² Working reduces financial problems and provides parents with a break from caring.

'Without being able to utilise these flexible working arrangements my single parent household would not function, I could not maintain my mortgage etc.'
Father office worker⁷²

'It [flexible hours] will make life easier if my son has hospital/doctors appointments, I can take him without losing annual leave.'
Mother office worker⁷²

'I go to work to escape; I go to work to keep sane.'
Parent⁷²

Housing and adaptations

What is the situation?

When it comes to housing needs, disabled children and their families need more than just physical access. Adequate internal space, suitable adaptations and equipment, safe outside space and location, are all important. Having appropriate housing is fundamental to living a normal family life; poor quality or inaccessible housing is hugely damaging to the quality of life of a disabled child and his or her family. As many as three out of four families with disabled children live in unsuitable housing.²⁹

Children's chances of enjoying normal childhood experiences can be seriously restricted by living in homes ill-suited to their needs. Inappropriate housing hampers movement, play and normal family activities, as well as exercise, therapies and personal care. It places families under increased physical and mental stress. For example, homes with no downstairs toilet can cause back injuries for parents who carry or help children up and down many times a day. A lack of space restricts the mobility of severely disabled children. They may be unable to play with brothers and sisters or have a no privacy.⁹² Siblings sharing a room with a disabled brother or sister may lack a quiet space for homework or may be disturbed by sleep or behaviour problems.

Research shows that the housing conditions of families with severely disabled children are worse than those of families on similar incomes with non-disabled children. Statutory support fails to address their needs adequately. A 1998 study found that families of children with behaviour and or learning difficulties are more likely to face problems with the location of, and, safety in the home. Families of children with physical impairments or a serious health problem were more likely to report problems with access and storage of equipment. In total, 55% of families reported problems due to a lack of family space and 42% stated that kitchens or bathrooms were difficult to use or that they only had one bathroom (41%) (See Table 5).⁹²

Children's chances of enjoying normal childhood experiences can be seriously restricted by living in homes ill-suited to their needs.



Photograph supplied by Mencap

Only 2% of families can afford to make the contribution they are supposed to make to meet the cost of adaptations.

*'Mr and Mrs A lived in a four-bedroom house on an estate with a bad reputation on the edge of the city. They had six children, two of whom were severely disabled. One child had a serious heart problem and the other had cerebral palsy. Their 'people carrier' financed through the Motability scheme, was frequently vandalised, but was too big to go into the local garage block. The family reported that their council had been very dismissive of them when they asked if their garage could be made larger. A specialised buggy had just been stolen from the shed. The garden was unusable — it had neither grass to play on, nor a hard surface. The family had had graffiti daubed on their walls and one of the boys suffered sexual abuse from a neighbour. The house was in poor repair and very cramped.'*⁹²

The study also found that:

- Housing problems are linked to poverty among families with disabled children, but even middle-income families with disabled children experience considerable housing problems.
- Compared with families on similar incomes, families with disabled children are more likely to rent than own their home.
- Families with disabled children who rent from a local authority or a private landlord are likely to have more problems than those who rent from housing associations or who own their home.
- Non-white families with disabled children were less likely to be living in a suitable home than white families with disabled children.

- Most families had moved house at least once as a direct response to their child's needs. The majority of these families had received no professional advice or assistance with finding a suitable alternative home.

What is the government doing?

The Disabled Facilities Grant (DFG) (see Table 4 in financial section) is the state's contribution towards the cost of providing adaptations and facilities to enable a disabled person to continue to live in their home. An assessment of needs is made, usually by an occupational therapist from social services, and an income-based means-test is carried out to assess the contribution towards the cost of adaptation that parents must pay. The maximum DFG is £25,000. It cannot be used to help the cost of families moving house if the necessary adaptations are not practical in the current home. There is widespread recognition that the means test is at best inadequate, and at worst unfair.

Means-testing the DFG is seen by many as unfair for a number of reasons. The test used is one of income, which fails to take into account family expenditure or the increased cost of having a disabled child (see Box 13). Parents are sometimes assessed as having to contribute thousands of pounds towards the cost of adaptations. For example, families on an income of £40,000 per annum are expected to contribute £81,000 towards the total cost of adaptations. Only 2% of families can afford the contribution they are supposed to make.⁹³

Table 5: Housing problems for families with severely disabled children*⁹²

Housing problem area	% of families reporting problems
Lack of space to play, or space apart from other family members	55
Functional rooms (kitchen, bathroom, toilet) difficult to use because of size	42
Only one toilet and/or bathroom	41
Lack of storage space for equipment	38
Location	38
Access around, and in and out, of the home	33
Lack of downstairs toilet and bathing facilities	33
Housing condition	27
Lack of space and equipment to carry out therapies	21
Inadequate facilities to meet care needs (e.g. lifting, toileting and bathing)	21
Child's safety inside the home compromised	3

* Data from families comes from FF database and therefore is not representative of all families with a disabled child, but, is comparable with families on low incomes without a disabled child.

Families either go into debt to finance the work, or they don't have it done and continue to live and care for their children in unsuitable homes. One study found that of all families assessed as needing adaptations, one third made the required contribution; a further third had been unable to, so the adaptation was not carried out.⁹² The means-test penalises those families who save the state large amounts of money a year by caring for children in their own home.

In one study, three quarters of families reported that an occupational therapist had not assessed their housing needs. Families who had been assessed did not always get the necessary adaptations made. Others were waiting for vital adaptations or to be re-housed by housing associations or local authorities.⁹² A study by the Office of the Deputy Prime Minister (ODPM) found that it was common for disabled people to wait a year or more for adaptations. When adaptations are assessed as necessary, the DFG is mandatory (assuming parents can make their contribution). This means the only way for local authorities to ration the fixed, inadequate and shrinking (in real terms) pot of money for the DFG is through waiting lists. Increasing numbers of elderly and disabled people means increased pressure on the DFG money.

Administration of the DFG is also complex for clients and social services staff.⁹⁴ Another study reported a lack of clarity about roles and responsibilities across the various (and numerous) practitioners and departments involved in the DFG, and failure to work in a joined-up manner. Failure to understand needs and provide information on entitlements were also common.⁹²

Some families rely on support from their local community to raise funds for their contribution to the DFG (see Box 14). Although the community may be happy to oblige, it does not make it right. If a health professional has assessed that a child needs housing adaptations (which often reduce the value of a property), adaptations should be made as soon as possible, without an unrealistic and unfair contribution from parents. The DFG means-test for children should be abolished. After a successful campaign by parents and the Homes Fit for Children group of charities, means-testing was recently abolished in Northern Ireland. Lobbying is now happening to achieve the same in England and Wales. In order for abolition of the means-test to be fully effective, local authorities must allocate extra resources.

What is the charitable sector doing?

ASBAH, Barnardo's, Child Brain Injuries Trust, Contact a Family, Council for Disabled Children, Down's Syndrome Association, Family Fund, HoDis, Mencap, Muscular Dystrophy Campaign, NCH, Parent Project UK and Scope are involved in the **Homes Fit for Children campaign**. Their aim is to have the means-test abolished.

What are the outcomes of attending to housing needs?

The home is the centre of family life. For disabled children and their families, whose lives are impeded by poor services and ignorant public attitudes, it ought to be a sanctuary. The family home is where disabled children receive personal care. Care in an unsuitable environment is demeaning and inappropriate. Improving the homes of disabled children is a tangible way of improving their quality of life.

'We were desperate for the work to be done, because every time he wanted to go to the toilet he had to crawl upstairs, so I didn't like that. And if there are any guests, Chris does not like crawling in front of them, so now he is all right and he has the freedom to go to the toilet, watch telly...'
Parent⁶

‘If you can get your home right, you can cope. Within 24 hours of being in this house, it was like wow! She was a different child.’

Mother of a severely disabled girl after moving to a well adapted home⁹⁷

Box 13: Fighting the system

'We were recently driven to take our case to the High Court out of sheer desperation because of the need for special equipment for our boys. Our local authority has always maintained that we should apply for a Disabled Facilities Grant (DFG). Because we have more than £15,000 in assets, we would be means-tested and we knew this would result in us having to meet the whole cost ourselves.'

The difficulty with means-testing is that it doesn't take into account our debts or outgoings — we have no spare cash to buy £40,000 worth of equipment. Loving the boys has cost us our livelihoods as we simply don't get enough hours of domiciliary care to enable Michael or I to work.'

As a result, the children are left with nothing and the local authority walks away.'

In October 2004, the Spinks lost their High Court battle for help towards funding the £40,000 worth of equipment their disabled boys need.

Henrietta Spink⁹⁵

Box 14: Fundraising for DFG contribution

'In order for Tilly to enjoy independence in our own home, a specially designed and equipped ground floor extension would need to be created. Following months of stress, it was agreed that the statutory Disabled Facilities Grant would fund approximately half of a £60,000 project.'

Finding £30,000 is beyond the average family, so once again we turned to the community for support. They didn't let us down. [...] I don't think there is a single member of the community who has not made a contribution to our daughter's happiness.'

Parent⁹⁶

Box 15: A day in the life of Henrietta Spink

'I wake at 2.30 a.m. to change Henry's nappy and just can't get back to sleep. By 4.30 a.m. I finally manage to nod off. The alarm clock peals at 5.30. My eyes yearn to stay closed but I force myself out of bed — our schedule is tight as the bus comes at 7 a.m. to pick Henry up. Freddie's comes half an hour later. It takes both of us an hour and a half to get the boys ready for school.

I rush down to prepare breakfast. It isn't just a question of pouring out the cereal and a quick drink of milk. There are endless supplements and medication to prepare for each child. I've got my time down to fifteen minutes on each task. Then it's back upstairs, where Michael is getting Freddie dressed. I finish him off and take him downstairs and start his breakfast. He has all his medication at the start so that we don't miss any out. I send in emergency medication to the school just in case one of us does forget something in the rush. He suffers terribly if the antacids are not given.

Michael gets Henry dressed and brings him downstairs. Either I feed Henry or Michael does. Henry's not easy to feed. Most meals take an hour — that's three hours a day just shovelling food. No wonder he doesn't like meals — he's probably as bored as we are. He has an amazing habit of flicking the spoon out of your hand just as you get it to his mouth and the cereal flies everywhere. Ideally it takes two people to feed Henry, one to hold his hands, but we can't afford that luxury most days.

While one of us struggles to feed Henry, the other takes Freddie to the loo and puts on a pull-up for the bus journey. It's impossible for the bus to stop en route for Freddie if he needs to, and it's the only way we have of keeping him dry until he arrives at school. Toileting Freddie takes about fifteen minutes. Then it's back downstairs where the other has hopefully finished feeding Henry. Sometimes, despite the overall we put on him, Henry is completely covered in milk and cereal and a complete change of uniform is needed. The boys have about eight full uniforms each to cater for the constant changes they require. Finally we get their coats on and the bus comes.

As soon as the boys are gone I change Henry's sheets, which will inevitably be wet or sicked on...It's rare that I don't have to change his bedding in the morning. When I get to Freddie's room my heart beats faster. I never know what I'll find. All I do know is that there will be at least an hour's work dealing with whatever is involved...he might — and this is the one I dread most — have done a poo and spread it everywhere.

By nine o'clock I feel fairly tired. No time for that — need to clean the house...It takes forty minutes to an hour on average to do the laundry — the boys seem to pee and dribble an awful lot. Then it's another hour to prepare food that they 'will' in Henry's case, and 'can' in Freddie's, eat...

Feeding, bathing and toileting the boys takes two to three hours every evening, if we're lucky. Henry usually sits for at least forty minute on the loo and someone needs to sit with him at all times because he can unexpectedly fit. He likes to be entertained, so we read to him...

The boys are up at 6 a.m. Saturday morning. The same arduous day begins all over again, but this time there's no carer and no school, it's just Michael and me, facing the prospect of round-the-clock care for the next forty-eight hours.¹

*Henrietta Spink, mother of Henry (16) and Freddie (12), both disabled boys*¹⁰

A recent survey showed that 80% of families had reached breaking point.

Short breaks

A recent Mencap survey found that 80% of families with children with severe or profound learning difficulties had reached breaking point.⁹⁸ Although these families choose to keep their children at home, the physical and emotional strain is immense. Parents and carers suffer innumerable sleepless nights and spend their waking hours caring for their children.* An earlier Mencap survey found that this care takes up at least ten hours of a parent's day; it can also involve night-time care.⁹⁹ Parents not only care for their children at home, but accompany them to numerous appointments. Three quarters of profoundly disabled people visit a hospital up to ten times a year. At least 50% are in contact with a healthcare professional almost every day.¹⁴ Caring for a disabled child is highly intensive and can be a life-long commitment.

'My own health has deteriorated. I have suffered with depression for over two and a half years. I don't feel I can ever get off tablets. I have anxiety attacks that feel like I am having a real heart attack. I am only 26!' Parent⁹⁸

A break from this care provision is vital for the well-being of the carer. It also provides a good opportunity for the disabled child to have a break from the carer. It may enable the child to have new experiences, meet new people, develop new relationships and enjoy leisure activities. Small breaks from caring are often the only things that prevent families from reaching breaking point.

What are short breaks?

A short break is 'A session, or more, of care or support that enables disabled or vulnerable individuals to spend time away from the person(s) who provide them with regular and substantial care. Such breaks can be provided in the individual's own home or in another setting, but no break should exceed one month's continuous care.'¹⁰¹

Traditionally known as 'respite care' (see Box 16) and consisting largely of residential care, short break services now include:

- Shared care schemes (also known as 'family-based' or 'family link' services) — a disabled child spends time out of their home with another individual or family (may be day or overnight care).[†]

'It's a real treat to have a shower.' Parent⁹⁸

* As many as 45% of children in special schools wake up regularly at night, compared with 13% of children in mainstream schools.²⁹

[†] These family-based short breaks have been available since 1976 when two local councils (Leeds and Somerset) set up pioneering schemes. Before this, short breaks were predominantly provided in hospitals or hostels.

- Residential services. These are usually overnight services in an institutional setting or residential unit, funded by statutory services.
- Domiciliary services (also known as ‘outreach’ services). Services are provided in the child’s home, usually by the statutory sector.
- Sitting services. Care that takes place in the child’s home; usually provided by a registered sitter (not funded by statutory services).
- Befriending schemes — a one-to-one relationship (usually with a volunteer) that enables a child or young person to access a range of community or leisure activities.
- Community and leisure activities. Care is given within a range of organised group activities, such as play schemes, after-school clubs, youth and weekend clubs.

There are an estimated 189 shared care schemes in England, Wales and Northern Ireland for disabled children and adults.¹⁰² The primary service provided by these schemes is short breaks away from home with a support carer. Of the children’s schemes, 45% provided sitting services, 32% befriending services and 25% other services, including youth clubs or holiday placements.¹⁰³ This diversification is driven by number of factors: the changing population of disabled children; the move towards inclusion of disabled children into mainstream services; a move to providing services that benefit the child as well as the parents; and the increasing difficulty in recruiting carers to provide overnight short breaks¹⁰⁴



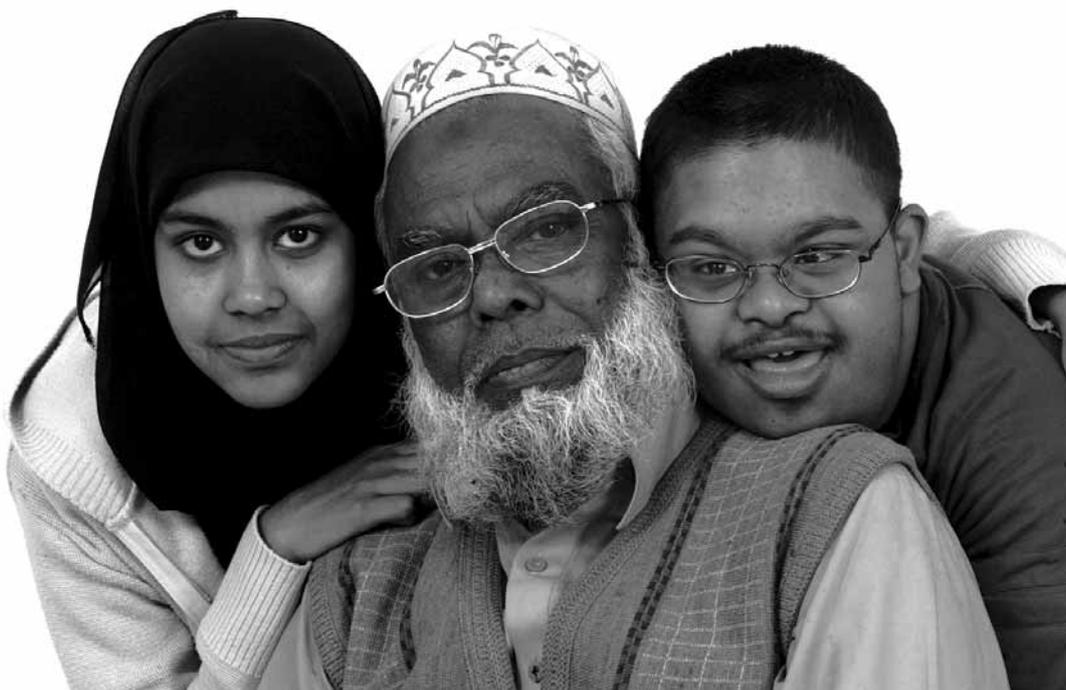
Photograph supplied by Shared Care Network

Box 16: From ‘respite’ to ‘short breaks’

The Oxford English Dictionary definition of ‘respite’ is:

‘n 1: a short period of rest or relief from something difficult or unpleasant; 2: a short delay permitted before an unpleasant obligation is met or a punishment is carried out. v 1: postpone (a sentence, obligation, etc.); grant a respite to (someone, especially a person condemned to death).’

These definitions have negative connotations. They imply that carers do not enjoy being with their children, that caring is an unpleasant burden. Because of this, respite care is increasingly referred to as short break care to show that it provides a break both for the carer and the child — and that it is often enjoyable for both!



Photograph supplied by Shared Care Network

The majority of short break services are provided by local authorities.

Who provides short breaks?

Residential care can either be provided by local council in-house provision, health trusts, hospitals, boarding schools or by the independent sector, both charitable and private. Local authorities provide most shared care services — a 1998 study of 204 shared care schemes found that charities controlled only 25%.¹⁰³ All of the schemes are funded, at least in part, by local authorities. The largest charitable sector providers of short break services are Barnardo's and NCH; approximately 80% of their local scheme costs are paid for by local authorities.

The typical amount of care provided by shared care schemes is one 12-hour session per week with an average cost per child of £1,767 per annum.¹⁰³ Because these schemes predominantly use volunteer carers, they are the most cost effective type of short break. A study of the South West found that the average daily cost of residential services was £176. The highest average daily cost was in NHS units (£241) and the lowest was in residential schools (£98).¹⁰¹ In London, NPC found the cost per child per night for short breaks ranges from £300-450.¹⁰⁵

How many people receive short breaks?

In 1998, the Department of Health estimated that 10,000 children and their families benefited from short break services.¹⁰⁶ This represents just 1.4% of all disabled children and less than 15% of those with severe learning difficulties.* Recently, the Department of Health reported that only one in five people with a learning disability known to social services is getting a break.¹⁰⁷ In one week in 2003, a reported 29,700 disabled children received any form of support from social services and around 8,100 children (disabled and non-disabled) received respite care.¹⁰⁸ At a local borough level, numbers indicate that 1–10% of disabled children are receiving short breaks from social services.

'Duke relies on me, but I can't rely on Social Services to pay for the services that Duke needs or to help me take care of him. I have paid with my marriage and with my health. All I need is a bit of help with Duke. Is that so much to ask?'

Parent⁹⁸

Although exact numbers are unknown, it is clear that far too many carers are not receiving any short breaks. If they are, the provision is so minimal it makes little difference. The Mencap survey found that 60% of families were getting no short break services at all, or services so minimal as to not meet needs.⁹⁸ This is consistent with its earlier survey, which found that 48% of families received no help from outside the family and a further 30% received less than two hours support per week.⁹⁹

The Audit Commission states: *'What is provided is often too little and too late to make the best possible improvement to their everyday lives'*. It gives an example of a single mother with three children — two of them autistic and one with Asperger's Syndrome. The mother was struggling to cope, but the children did not have the 'complex' needs required to meet criteria for short breaks. Nor did they have the 'severe challenging behaviour' required to be eligible for health short breaks. The health short break service finally offered to 'help out' for a short time only, because it could not help with the social need for a break from caring.⁶

One study found that almost 90% of shared care schemes had waiting lists. The numbers on the waiting lists were equal to half the number of children actually receiving services.¹⁰³ A third of all users wait over a year for services. These numbers, although startling, are conservative because they only include those children who are referred to services (usually by social services) and who meet the eligibility criteria. Over 85% of schemes were found to have eligibility criteria. Although most schemes cater



Photograph supplied by Shared Care Network

* The Department of Health estimates that 65,000 children and young people have severe and profound learning difficulties.¹⁴

for people with learning difficulties, the criteria often exclude those with complex health needs or challenging behaviour — those who most need a break. In particular, children with autistic spectrum disorder and technology-dependent children have difficulty accessing short break services.^{109, 110} A recent study found that over half the sample received neither domiciliary care or care away from the home; many received insufficient or inflexible support.¹⁶

'They wanted us to try a respite family, but they couldn't find a family that would take her. By the time she was six, we had been through four families and the last family had her for about an hour-and-a-half and they brought her back and said 'sorry, we can't cope'.' Parent¹¹⁰

Another group receiving proportionately less provision is black disabled children and their families. A 2002 study found that the take-up of short breaks by black families had not improved over ten years. A disproportionate number were using institutional rather than family-based provision, compared to white families.¹¹¹ Although home-based services are particularly popular among this group, a lack of communication about services, concerns about the appropriateness of services and a shortage of black social workers and short-break carers are acting as barriers to access.

The main reasons quoted for this huge level of unmet need across the board are a shortage of funding and a shortage of support carers. Shared care services often have a low status within social service departments, resulting in under-investment.¹⁰³ Services are budget-led, rather than needs-led. This lack of resources prevents schemes from: raising their local profile; pro-actively recruiting a diverse range of carers; providing appropriate training; providing enough support; paying carers appropriately and providing equipment to carers.¹¹² The result is too few services for too few children and their families. A rough estimate of additional funding required to serve a further 50,000 of the neediest families is £100 million per annum.*

As well as a lack of funding, recruitment is hampered by regulatory requirements, assessment procedures, training, lack of staff to focus on recruitment and the relatively long-term

commitment required of carers. In order to bolster recruitment, payments to support carers have been increasing. Payment to children's support carers in 1998 averaged £16.22 for 12 hours.¹⁰³ However, a study of ten short break schemes in England, Scotland and Wales in 2003 found that although paying a salary to carers improved the stability of placements and provided care for children with more complex needs, there was no consistent impact on waiting lists.¹¹³

10,000 children and their families benefit from short breaks. This represents less than 2% disabled children.



Photograph supplied by Merseyside Access to Play

90% of shared care schemes have a waiting list of half the number of children they serve.

‘ We can take only the tip of the iceberg. Many children don't meet our criteria and they might have quite complex needs but they don't have palliative care needs or degenerative conditions so they get nothing. ’

Service manager⁶

* £2,000 x 50,000 families = £100 million. This represents 0.025% of annual government expenditure.

I cried bitter tears that I could not even attend my father's funeral without a battle for care for my children. I don't think I have ever felt as alone as I did that day. ⁹⁸
Parent

What is the government doing?

Under the Children Act (1989), support services must be provided to disabled children (classified as 'children in need'). Furthermore, under the Carers (Recognition and Services) Act (1995), social services must assess the needs of the carer as a separate activity from the assessment of the child's needs. However, the Mencap survey found that 60% of families had never had a Carer's Assessment.⁹⁸ Even if the needs of the carer are assessed, there is no legal obligation for the government to provide short breaks. Without a statutory right to provision, many carers either get put onto a waiting list or have to fight continuously for any service provision at all.

The government has come to recognise the importance of short breaks. The Social Services Inspectorate (SSI) claims that they are 'almost universally regarded by parents as a critical service in supporting families within the community'.¹⁰⁶ The Quality Protects initiative for transforming children's services in England specifically promotes the increased provision of short break services to disabled children and their families.¹¹⁴ The central government has introduced changes, such as the Carers Strategy (1999) and provision in the Carers Act (2000) for local authority social services departments to run short term break voucher schemes. Short term break voucher schemes offer flexibility in the timing of carers' breaks; the people being cared for can also choose how community care services are delivered to them while their usual carer is taking a break.

Additionally, Direct Payments have been extended to parents and carers of disabled children to purchase their own care.

The government has also provided extra money for services. For example, the Carers Grant to take short term breaks is increasing by £60 million to £185 million by 2006, and the Carers Special Grant will be ring-fenced until 2004/2005. The Children's NSF includes standards that ensure short breaks are offered without 'undue delay' and that there are a 'range of services from which to choose', including home, family-based, residential, community-based, sitting services and Direct Payments.⁴⁷ The DfES has commissioned a document to guide local managers and practitioners on how to implement the NSF standards. However, these initiatives and funds do not seem to have translated to local provision yet. A dramatic change is needed in funding, recruitment and training of carers if demand is ever to be met.

What is the charitable sector doing?

Both **Carers UK** and **Contact a Family** support carers via helplines and online information. They inform carers of their rights and how to approach social services for provision. They will write letters on behalf of carers to local authorities and will also put the carer into contact with local support groups and shared care schemes. They also lobby the government on carers' rights.

Shared Care Network (SCN) is a charity that acts as an umbrella body for approximately 174 member shared care schemes across the UK. It lobbies the government, disseminates information and best practice and assists in recruitment of carers (e.g. by providing posters and information and co-ordinating 'Share the Care' week). Recently, the DfES commissioned it to produce guidance on implementing the standards around short breaks in the Children's NSF. It also commissions the regular 'state of the nation' study of its member shared care schemes.

In addition to these three organisations, the **Council for Disabled Children** and **Mencap** are both active in the campaign to increase the level of provision of short break services.

Funding local providers of short breaks, such as **Barnardo's**, **NCH**, **KIDS**, **The Children's Trust** and **Crossroads**, is more difficult because short break services are provided under contracts with the local authority. Any additional charitable income is generally not used to increase the quantity of provision because of the concern of crowding out statutory provision and/or funding. The charitable income may be used to increase the quality of provision (for example, by providing better equipment or funding building upgrades) or to fund increased local advocacy. This in itself is often problematic because the local project is dependent on the local authority for survival.



Photograph supplied by Shared Care Network

What are the outcomes of short breaks?

The outcomes of short breaks are difficult to measure but the services should be seen as beneficial per se. The more high quality services provided the better. Short breaks provide both the carer and the disabled child with much needed time apart and allow both to focus on something different. For the parents, time away from their disabled child to be with their partner and/or other children is the single most important factor in helping their relationship.⁶¹ For the child, short breaks are an opportunity to meet new people, to develop relationships and to gain some independence from their carer. The national survey of short break schemes in 1999 interviewed a small number of children. It found that they enjoyed the experience and the relationships with their carers, and that they benefited from the wider social activities and networks opened to them.¹⁰³

'We love Nathan to bits, but this gives us time to devote to our other son who misses out a lot. We can also do things we cannot do with Nathan. It gives us time as a couple. It can sometimes be the light at the end of a tunnel. If we have had a really bad weekend, knowing Nathan is going to Carol and Rob's helps us carry on. He loves spending time with Carol and Rob. He really enjoys going, so we are happy because he's happy. They spend a lot of time in the garden with him, which he loves. He has a flair for it and meets a lot of people. He is well known where they live and they all accept him for who he is. He is safe. Knowing Nathan can go somewhere where he is happy, safe and he enjoys is wonderful. If it wasn't for Rob and Carol and people like them, we do not know what we would do.' Parent¹¹⁵

'He doesn't have a group of friends...he doesn't go anywhere and he goes to a special school out of the borough, so there is no one he sees regularly. I know it sounds a bit over the top but I think for Toby this [his short term break] may be the single most important thing that has ever happened to him.' Parent³⁷

'I need a break from my mum, I stay in all the time, I never play out by mine.' Disabled child¹¹⁶

For an annual cost of £1,767 per child, short breaks can prevent residential care costs of up to £300,000 per annum.

It's good because it gives you a break from your parents and your parents a break from you.¹¹⁵

Disabled young person¹¹⁵

Short breaks can reduce family and carer stress, which has been cited as a major reason for placing a disabled child in residential care.¹¹⁰ Just under £2,000 per child per year should be compared with the annual costs of residential care, which range from £50,000–£300,000.^{98, 117} Foster care can cost £750 per week including training, short breaks and support for the foster family.¹¹⁸ The Children in Need Census of 2003 found that a looked after* disabled child cost local authorities £635 in the survey week, whereas supporting a disabled child within their family cost £150 per week.¹⁰⁸

Whichever figures one considers, at less than 25% of the costs of caring for the child following family breakdown, short breaks are a worthwhile investment, even if they only prevent one in four carers from reaching breaking point.



Photograph supplied by Shared Care Network

* Children who are cared for by social services are described as 'looked after'. They are often placed in residential children's homes or foster care.

“The first cost is the emotional cost, you’re devastated and scared.” Parent⁶⁶

“You don’t want to go out with them... because people stare, and you are his sister, but you are holding his hand to make sure he doesn’t run away.” Sibling⁶⁶

Emotional support

Although this report has illustrated the high financial cost of having a disabled child, it is the emotional cost, the impact on family life and the feeling of isolation that parents find the most difficult to bear. Parents often feel they have nobody to speak to and that no one understands their situation. Families may be unable to attend mainstream activities or visit friends, which increasingly leads to social isolation. Families value counselling and peer support. Emotional support enables them to better meet their children’s needs.²⁹

‘The whole of my life is centred around Richard. I have had no social life, no life of my own.’ Parent⁶⁶

The impact on siblings

Having a disabled sibling has a dramatic impact on a child. The experiences of siblings of disabled children are distinct from other children. There are an estimated two million people of all ages with a brother or sister with special needs, disability, or chronic illness in the UK.¹¹⁹ Younger siblings often lose out on care; their relationships with parents suffer as a result. Older children may end up taking on a caring role. Parents often worry that this causes siblings to grow up too quickly.

‘I’ve got a six-year-old [non-disabled] child who is like going on 40, you know he’s like a little old man and sometimes you think, that’s awful because they don’t get a childhood. And some of the things he comes out with I think, ‘oh dear’. And they have all their worries and all their problems and they’ll be upset one day and you ask, ‘What’s the matter?’ And I’ll say, ‘Why didn’t you tell me?’ and he says ‘Because you’ve got too much else to do.’ Parent⁶⁶

Siblings of disabled children may also be isolated from their peers. It is difficult for parents to take them out, or have other children round to the house. Parents may feel reluctant to let them go to friends’ houses because they feel guilty about not being able to reciprocate. Disabilities may affect siblings’ ability to play together, further contributing to loneliness and isolation of non-disabled siblings.

Children often have a lot of questions relating to their sibling’s condition (particularly if it is life-limiting). They worry that they may develop it, or pass it on to their own children. Often, they don’t feel able to ask parents about this for fear of upsetting them. Siblings’ education may suffer as a result of being constantly tired because of interrupted sleep. They may be bullied at school because of their brother or sister’s disability. Doing homework may be impossible because of disruptive behaviour of a sibling. It is often siblings who find the negative public attitudes towards their disabled brother or sister most upsetting. All of this can lead to feelings of resentment, followed by guilt about having these feelings.

*‘Dominic bites a lot. I don’t know why. I think it’s his way of kissing. He only usually bites when he’s affectionate, not when he’s angry. That’s what the doctors say and I believe them. He only bites when he’s having fun. It’s all right. You can kind of forgive him. When he’s cross it’s horrible. Once he got on my back and wouldn’t come off. He bit me through my pyjamas. I was giving him a piggy-back and he bit me. It spoils things a lot. You’re having a really nice time. It’s hard. I want to believe what the doctors say. I know where they’re coming from. My step-dad’s brother got bit. It was hard to tell him. He didn’t quite understand. Dominic’s getting out of the habit of biting. Now he’s pulling hair.’*¹¹⁵

*‘My sister gets support in the hospice and gets to go on holiday. Me, I’m stuck at home. It would be nice if stuff happened to me.’*⁶⁰

What is the government doing?

The Children’s NSF recommends that appropriate mental health services are made available to siblings of disabled children. Furthermore, the Children Act (1989) provides the framework for support offered to children ‘in need’. Although siblings of disabled children aren’t explicitly catered for in the Act, the Guidance and Regulations of the Children Act which refers to disabled children states: ‘the needs of brothers and sisters should not be overlooked and they should be provided for as part of a package of services for the child with a disability.’¹²⁰ If the sibling is providing substantial amounts of care they may be entitled to an assessment of their needs in their caring capacity. Either way, the needs of siblings should be assessed by local authorities where appropriate. There is little evidence to suggest that this is happening.

What is the charitable sector doing?

The emotional support of families is one area where the government has few obligations and the charitable sector has a significant role to play. Most emotional support comes from personal contact, usually facilitated by a local parent group or a single condition charity. Parent support groups meet on a regular basis, both for social purposes and as a way of exchanging information. **Contact a Family** provides a Family Group Action Pack, which provides information on setting up and running a support group. It can also administer grants to groups on a donor’s behalf.

Contact a Family and **Carers UK** provide details of local parent organisations to families via their helplines. Contact a Family also provides details of any relevant single condition organisations. These **single condition charities** often become the first point of call for parents. They typically act as one-stop-shops for information about the condition and the relevant services. Many organise social events where families meet others in similar situations. **Syndromes Without a Name (SWAN)** provides support for families with children who have no diagnosis. Where a single condition charity does not exist, **Contact a Family** will provide links to parents of children with the same condition. It also produces factsheets for grandparents and fathers.

Services for disabled children are increasingly inclusive of all family members which creates opportunities for socialising. NPC found a number of holiday, days out and play group providers where the entire family was welcome. A number of charities have recently developed siblings groups. This idea is well established in the US, but is just starting to take root in the UK. These groups usually consist of around eight children in a fairly narrow age range. The group is confidential and meets weekly over 6–8 weeks and then again at regular reunions.

'It helped to know that I'm not alone with a disabled brother or sister.' Sibling ¹²¹

Sibs is a relatively new charity that offers an advice and support line for siblings and professionals. It also provides help and training on setting up sibling groups. It has produced a set of factsheets in many languages aimed at both siblings and professionals.

Short break service providers, such as **NCH**, **Barnardos**, and **KIDS**, run sibling projects as part of their local service provision in some areas. The funding for these is mixed; the majority is from statutory streams, such as the Children's Fund. **PSS** and **Choices Project (Merseyside Youth Association)** both include siblings of disabled children in their play and leisure services.

Carers UK informs and advises young carers via its helpline and website. **NCH** and **The Children's Society** also assist young carers.

Genetic Interest Group provides screening services for families of disabled children. It also has a resource pack for brothers, sisters and parents of people with a genetic disorder.

Sibs offers an advice and support line for siblings and professionals.

Section summary: families

Families with a disabled child are one of the most disadvantaged groups in society. They are disproportionately likely to live in poverty and have high levels of debt. This is because the cost of raising a disabled child is three times greater than for a non-disabled child, and parents are often unable to work because of intense care requirements. Most families do not receive any breaks from this care. Furthermore, nearly three quarters of families with a disabled child live in unsuitable housing. In addition to the practical difficulties, families often experience emotional devastation, anxiety and loneliness.

The government should do more to address the needs of disabled children and their families.

Visions and promises are not enough. It should:

- Increase the level of benefit (child benefit or DLA) and the take-up of DLA and child tax credits.
- Develop a Child Trust Fund for disabled children.
- Increase the threshold for eligibility for the Family Fund.
- Extend the use of Direct Payments.
- Eliminate the means-test and increase the maximum level of the DFG.
- Allocate specific childcare places for disabled children.
- Ensure local authorities provide short break services to a higher proportion of families.

Even though these measures require funds, there are economic and moral reasons to act. Supporting families before they can no longer cope is less costly and emotionally preferable to looking after children following a family breakdown. Providing appropriate childcare that enables parents to work is similarly economically beneficial. Last, but not least, social justice requires that the life chances of disabled children and their families are improved.

Given the government's responsibility, the role of charities might appear less obvious; however, it is no less important. Charities are often the first port of call for families. They provide emotional support, information and help in navigating and accessing the range of available benefits. As providers of services, such as short breaks, charities often use voluntary funding to experiment with new approaches, which are then rolled out under statutory funding. Charities also inform service providers around the country of changes to legislation, new approaches and activities. Most importantly, they lobby the government and support disabled children and their families to lobby for themselves. There is a strong case to support them in these roles so that families with disabled children — who are disadvantaged through no fault of their own — can lead ordinary lives.

Families with a disabled child are one of the most disadvantaged groups in society.

“We live in a society that sees people like my daughter as worthless. Why, then, would it be one that delivers high quality services?”

Parent⁹⁹

Parents want adequate financial resources and appropriate services that they have some degree of choice and control over, and that are reliable, responsive, and coordinated. They are not getting any of this, at least not consistently. This section explores what the government is doing to rectify the situation and how the charitable sector has a significant role in advocacy as well as in developing and disseminating best practice approaches.

A damning 2003 Audit Commission review of services for disabled children in the UK found: ‘a lottery of provision, a jigsaw puzzle of services, and too little provided too late’.⁶ The report set out a vision of effective services. Together with voluntary sector campaigning, it has ensured central government recognises the issues that disabled children and their families face. A number of pivotal documents addressing these issues were recently published. The most important documents were: the Prime Minister’s Strategy Unit’s ‘Improving the Life Chances of Disabled People’, the Children Act (2004) and ‘Every Child Matters: Change for Children’ programme and the National Service Framework (NSF) for Children, Young People and Maternity Services. Together with the Disability Discrimination Acts (DDAs), these documents set out compelling visions of a future where disabled children and their families can easily access services of their choice (whether mainstream or specialist) and are involved in the design and delivery of all such services.

However, under Labour’s ‘new localism’, an increasing number of responsibilities have been decentralised to local authorities and there is little ring-fencing of funds. This causes tensions between local democracy and the achievement of key government objectives for minority groups such as disabled children. This is leading to extreme variations in services because leadership, priorities, resources and budgets differ markedly between local authorities. The focus of voluntary sector lobbying needs to shift towards ensuring the compelling visions outlined centrally are realised on the ground. This is where private money can make the most difference to the lives of disabled children and their families.

Government context

Legislation

There are numerous acts covering the rights, as well as the education, health and social wellbeing, of disabled children and their carers (see Appendix 2). The DDA (1995) protects all disabled people from ‘less favourable treatment’ in access to education, services, employment and transport. The DDA (2005) extends the Act and places a new duty on the public sector ‘to promote disability equality’. The overarching policy framework for children’s services is contained in the Children Act (1989) and, more recently, the ‘Every Child Matters’ Green Paper and the subsequent Children Act (2004). ‘Every Child Matters’ lays out five key outcomes for children and young people’s well-being:

- **Being healthy:** enjoying good physical and mental health and living a healthy lifestyle.
- **Staying safe:** being protected from harm and neglect and growing up able to look after themselves.
- **Enjoying and achieving:** getting the most out of life and developing broad skills for adulthood.
- **Making a positive contribution:** to the community and to society and not engaging in anti-social or offending behaviour.
- **Economic well-being:** overcoming socio-economic disadvantages to achieve their full potential in life.



Photograph supplied by Epic Arts

The Children Act (2004) provides a framework for improving services for disabled children and their families. One of the primary aims is to improve access to services through better co-ordination of departments and service providers. To this end the Act:

- Makes provision for a Children's Commissioner for England.
- Places a duty on local authorities to make arrangements to promote cooperation between agencies and other appropriate bodies (through Children's Trusts), and provides a new power to allow pooling of resources in support of them.
- Requires local authorities to appoint a Director of Children's Services and designate a lead member for children's services.
- Establishes provision for databases containing basic information to enable better sharing of information.
- Calls for the creation of an integrated inspection framework and the conduct of Joint Area Reviews to assess local areas' progress in improving outcomes.

National policy

Legislation lays the groundwork for the rights of disabled people and the duties of the state. It is, however, only the beginning of national government involvement in the rights of, and services for, disabled children and their families. Parliament publishes regulations and guidance on how to implement legislation. It also develops national strategies (see Appendix 3 for relevant examples). These strategies have wide-reaching effects on how services are planned and delivered.

In January 2005, the government published the strategy 'Improving the Life Chances of Disabled People'. It sets out an ambitious programme of action to create equal opportunity for all disabled people and their families by 2025. The strategy calls for 'ordinary lives' for disabled children and their families. This is to be achieved by: ensuring all children receive childcare and early education; meeting the extra needs of families with disabled children; and ensuring services are centred on disabled children and their families, not on processes and funding streams.

A new Office for Disability Issues (ODI) reporting to the Minister for Disabled People will drive forward the strategy. Accountability for the implementation of the report will be through a Ministerial Group, reporting on an annual basis to the Prime Minister. The disability sector has widely welcomed the strategy but there are legitimate concerns about the actual commitment of resources needed to reach the vision. So far, the government has not announced any additional expenditure or programmes aimed at reaching the 2025 goal.

In addition to national strategies, central government sets national standards. The recently launched Children's NSF contains particular standards for services for disabled children and their families. The NSF states that disabled children and children with complex health needs should 'receive coordinated, high-quality child and family-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'.⁴⁷ Again, although the standards have been widely welcomed, there is concern that there are no targets, milestones or ring-fenced money for their implementation.

The mechanism to ensure implementation will be nine independent inspectorates and commissions, led by the Office for Standards in Education (Ofsted), who will monitor the national standards, along with children's services more generally. Assessment will focus on the five key outcomes for children and young people listed above. The draft assessment framework proposes that two groups of vulnerable children will be covered in detail in every joint area review: children and young people in care and children and young people with special needs and/or disabilities.¹²² The integrated inspection will feed directly into the comprehensive performance assessment (CPA) for local councils, by judging services for children and young people. Whether the proposed regime is enough to ensure a step change in the provision of services for disabled children and their families remains to be seen. Without additional funding, many doubt that it will.

There have also been many other initiatives and programmes (see Appendix 3 for a summary table of recent government publications and initiatives). One of the main concerns is that many of the broader initiatives overlook disabled children. The Audit Commission commented: *'disabled children's needs have too easily been overlooked within broader initiatives and funding streams, getting lost in the pressure to deliver and improve public services as a whole. As a user group, disabled children often speak with a quiet voice and tend not to gain attention as 'problem causers'*.⁶ The government needs to target disabled children and their families explicitly in all mainstream children's initiatives.

A new Office for Disability Issues is to be established to drive the government's strategy for disabled people forward.

Every joint area review led by Ofsted will cover children and young people with special needs and/or disabilities.

Box 17: Adam's story

Adam was born at full term, a healthy baby. At four weeks old he developed meningitis and spent the next three months battling for survival. Adam is now 13 months old. The effects of his meningitis are that he has cerebral palsy-spastic quadriplegia, is epileptic, blind and is fed by naso-gastric tube.

Despite this, Adam is a relatively healthy child and is large for his age. It is currently predicted that he will live until adulthood. Adam's family are coming to terms with his disability, but their life has been made far more difficult by fragmented and inflexible service provision. He has had 315 different service based appointments in the last nine months in over 12 different locations.

He has no control of his head, and was referred for a specialist buggy seven months ago. The family has yet to receive their first assessment appointment. They have been told that they will not be formally considered for aids and adaptations until he is three. This is despite the fact that he is now heavy; father and grandmother have already damaged their backs.

He has been referred for a gastronomy tube as the naso-gastric one is repeatedly being pulled out, he is often sick, the family are not confident at re-inserting the tube and the tape being used to attach the tube to his face is causing irritation and bleeding.

The family is now looking at moving into housing that can be adapted to meet Adam's needs. They require an assessment for aids and adaptations for the home. They have been told that they will not be eligible for a Disabled Facilities Grant because the father works. There will be no financial support for adaptation.

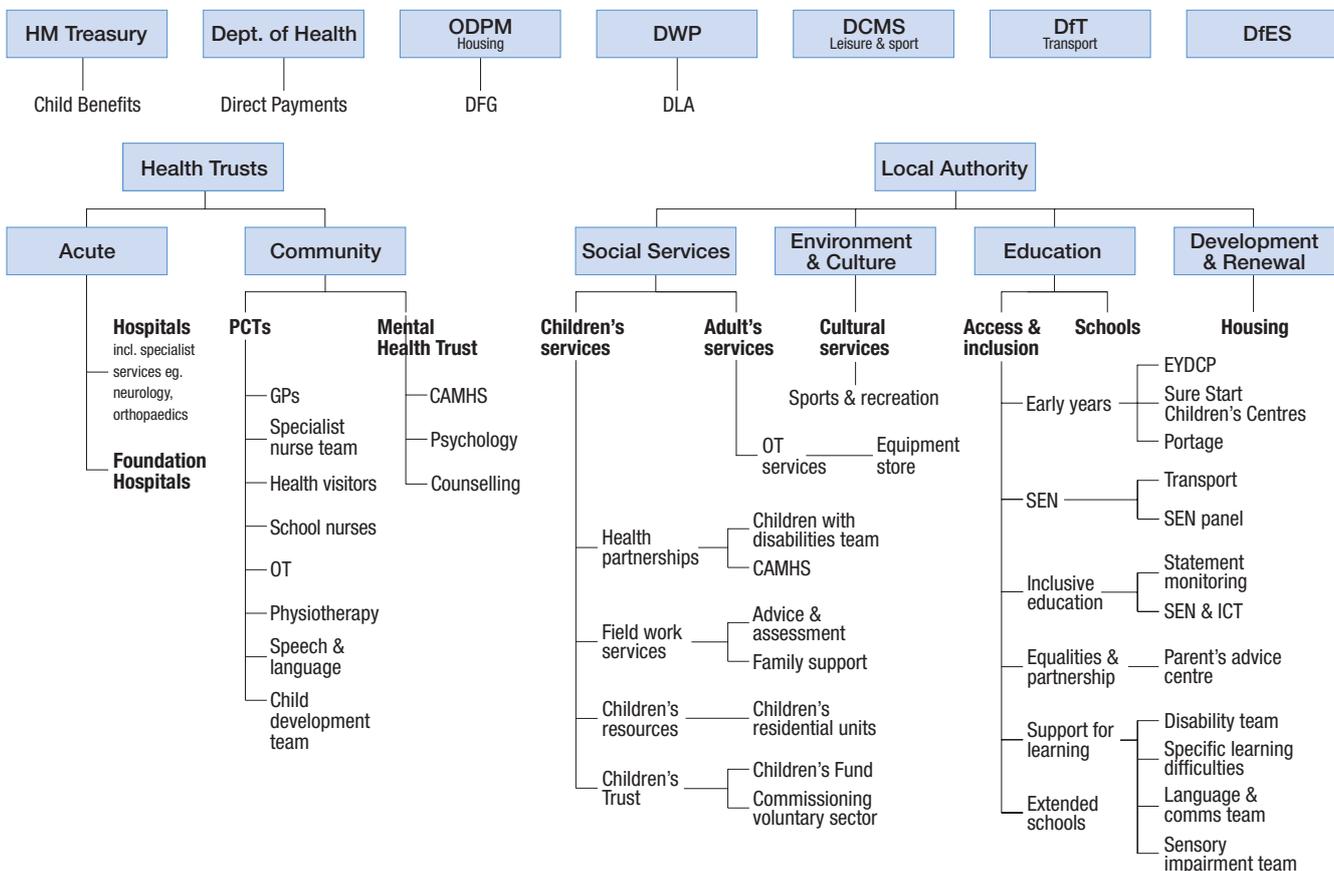
They have received no comprehensive information or support about their entitlements to benefits, access to counselling, or national and local support groups. They had limited access to a hospice, and support from the children's community nursing team. The family members report that the attitude of some professionals is still the most distressing thing they face.

'Together from the start' ⁵⁴

Local delivery

Too often disabled people feel they are fighting a fragmented, complex and bureaucratic system that does not put their needs at the heart of service provision. Families with disabled children have contact with an average of ten different professionals, and visit hospitals and clinics over 20 times a year.⁴⁷ Identifying and accessing suitable services in a timely fashion is a major problem for disabled children and their families. The Audit Commission found: *'for disabled children, young people and their families, navigating their way through the maze of services is a frustrating, time-consuming, repetitive and distressing process'*.⁶ Figure 9 illustrates the many agencies and departments disabled children and their families need to deal with on a regular basis. Information is not usually shared across these different agencies. Moreover, information on the wider population of disabled children (i.e. including those who do not meet eligibility criteria) is seldom collected, making planning and commissioning extremely difficult.

Figure 9: Illustrative statutory structure*



*Only the agencies, departments and units that have involvement with disabled children or their families are shown. The diagram excludes all charities.

'Please, just come and live and see what my life is like for a week and tell me you can cope with all this gobbledegook as well as coping with this from day to day. There has been no reforms that'll either benefit the parent or the child in the long run. No, because what we're given is just as soon taken away. Reformation of the system is urgently required with access to a central information bureau where parents can discuss education, health social and disability concerns with a real person, committed to reply to queries within a structured time limit.' Parent⁵⁸

Another problem is that there are not enough services for disabled children and their families. A minority have access to statutory services, such as childcare, leisure activities, equipment, financial support, and short breaks. One of the major causes of this is insufficient funding. This in turn is because of the lack of ring-fenced money, the low priority given to disabled children by local authorities⁶, and the increasing number of disabled children living in the community. In the past, the majority of disabled people lived in hospitals and health units. It is estimated that 98% of disabled children now live in a family home.³¹ Local authorities are therefore responsible for more disabled children than they were when the NHS or social security system funded residential care.

The lack of funding leads to eligibility criteria. These criteria are confusing, illogical and likely to change without notice.⁶ Lack of funding also leads to unacceptably long waits for services, equipment and adaptations. Assessments are based on what is available instead of what is needed. There are no statutory minimum packages of support. Services are uncertain and may be removed at any time depending on the budget. Local authorities spend most of their limited budget on very few children in a reactive way, instead of providing a greater number of early interventions.²⁹

Often the only redress for families of disabled children is the law. Many families end up at tribunal or in the courts trying to secure provision for their children and themselves. The worst case scenario for the local authority is that they have to provide what they are obliged to. Local authorities pay no legal costs, so they can draw out the process for as long as possible in order to avoid provision.

During its review of services, the Audit Commission did not find 'secure and comprehensive provision' at any of the five sites examined.⁶ Where services worked best, it was because of strong leadership and local champions who made the group a priority. The Audit Commission concluded: *'services for disabled children are still Cinderella services, and this disrupts children's life chances and worsens families' quality of life. In this context, improvement is critical'*.⁶

Having to reiterate in detail the exact nature of your child's disability is painful when you are working so hard to see him in a positive light. I would like there to be a central database, or 'passport', which confirms that my son has cerebral palsy for life and that I'm not lying.

Parent¹²³

Many of the national strategies and initiatives described above were developed to address these issues. The Children Act (2004) sets out a framework for improvement and co-ordination of services. It does this by creating a single point of responsibility for children's services and by recommending Children's Trusts and data sharing. Similarly, by using case files of disabled children in all joint area reviews, the monitoring system will ensure that this group are not overlooked.

Current national initiatives present a unique opportunity to turn this unacceptable situation around. The biggest challenge is to raise the profile of disabled children's services and make change happen at a local level.

Key workers

One way of addressing the fragmentation families face is to provide 'key workers'. Key workers act as the main point of contact for a family with a disabled child. They provide information, facilitate communication with the many service providers, and co-ordinate services within the care package. A key worker may be a professional already in contact with the family (such as a social or health worker), or it may be someone who works only as a key worker and has a caseload of families to look after. There is much experimentation with key workers at present. Standards have only recently been developed. The Early Support Programme estimates that establishing key worker services for children under three with complex and multiple difficulties would require an equivalent of one-and-a-half to two additional staff.¹²⁴

A number of evaluations show positive results. Families report improved relationships with service providers, fewer unmet needs and greater family well-being.¹²⁵ One study found that the impact on access to services was beneficial, but the social and emotional issues, as well as issues around funding and equipment, were still problematic.¹²⁶ Even with all the evidence of benefits, less than a third of families with severely disabled children have a key worker.¹²⁷

The Audit Commission did not find 'secure and comprehensive provision' at any of the sites they reviewed.

Fewer than a third of families with severely disabled children have a key worker.

The Norah Fry Research Centre undertakes applied research on services for people with learning difficulties.

'She's the health visitor and she's our friend and co-ordinator. If I need help, she's the person I'd turn to. I'd tell her anything. She helped me fill all my forms in, we had so much in our heads...Everything we had to find out we did through her. She came and did everything at home; it was a lot of help.' Parent ¹²⁸

Based on the positive evidence, Every Child Matters, the Children's NSF and the Prime Minister's Strategy Unit all recommend key workers. The Early Support Programme is funding the development of new key worker services on a range of models from 2004–2006. This includes the development of existing home visiting services, such as Portage (early years education provision), to take on broader key working responsibilities. Although the results generated by key workers are positive, their very necessity brings into question the entire labyrinthine structure of local service delivery.

Charitable sector

Improving services

Research, training and dissemination of best practice are vital to improve services provided for disabled children and their families. Charities (often funded by statutory sources) play a big role in all three of these functions.

Good research and evaluation underpin service development and are the starting point of intelligent advocacy. The body of research funded by the **Joseph Rowntree Foundation (JRF)** informed much of the ongoing advocacy around housing, costs of caring and levels of support required by families. Additionally, the research spearheaded the formation of 'best practice' groups, such as the Shared Care Network and Care Co-ordination UK. The majority of social research on disabled children is done by the two organisations described below.

- **The Norah Fry Research Centre (NFRC)** at the University of Bristol undertakes applied research on services for people with learning difficulties. Recent research on services and support for disabled children and their families has focused on multi-agency working, residential schools, children who are tube-fed, short breaks, Direct Payments and transition. NFRC is committed to including children, young people and adults with learning difficulties as advisers and researchers on its projects. It publishes all findings in accessible formats and has produced the 'Plain Facts' magazine and tape series (summarising findings of JRF funded research projects) for adults with learning difficulties. The centre is not funded by the university. It relies on external, largely charitable, funding.

- **The Social Policy Research Unit (SPRU)** is an autonomous research centre based within the Department of Social Policy and Social Work at the University of York. Its research focuses on people who are made vulnerable by poverty, unemployment, disability, chronic illness or ageing. It aims to influence policy and practice in order to improve the lives of these people. Researchers are involved in developing government policy (for example, two researchers were members of the Working Group on Disabled Children for the Children's NSF). The Children and Families team has published research on disabled children's participation, multi-agency care co-ordination, and the housing needs of families with disabled children. It also undertook a number of research projects as part of the JRF programme of research on disabled children.

The **Family Fund** also contributes to research by: maintaining its database of applicants; commissioning research using the database information; and disseminating its statistical report of applicants on an annual basis. The Fund's database is one of the main sources of data on disabled children and their families.

Research needs to be disseminated so that it can be used for planning and service development. This happens through conferences, networks, newsletters, training courses and guides and publications aimed at professionals. There are a number of national umbrella bodies that carry out these functions.

- **The Council for Disabled Children (CDC)** regularly sends updates and information on new research and best practice to the Association of Directors of Social Services (ADSS). CDC also uses ADSS for research purposes, for example, to establish variations in local practice and issues. It has published a number of guides for professionals, including those on Direct Payments ('Direct experience'), risk management ('The dignity of risk', with Shared Care Network), early support, parent participation (with Contact a Family) and implementation of the DDA ('Come on in'). In Spring 2005 it ran regional conferences to promote implementation of the Children's NSF and spread best practices. Its team of seven spends around half of its time in the field working with schools, local education authorities, strategic health authorities, primary care trusts and parent groups, informing and updating them on policy changes and best practice.

- **Care Co-ordination Network UK (CCNUK)** is an umbrella organisation promoting and supporting care co-ordination or key working for disabled children and their families. Based at the SPRU at University of York, it influences national, regional and local policy to promote best practice and to disseminate information. It has developed a resource pack aimed at managers and development workers responsible for setting up key worker services. It also created the national care standards ('New Standards for Key Working').
- **Shared Care Network (SCN)** is an umbrella body for shared care schemes. It does regular research through its members and collates and disseminates best practice among them. It also produces guides for those setting up shared care schemes and for professionals (it produced 'All kinds of short breaks' and co-wrote 'The dignity of risk' with CDC).
- **Sibs**, the umbrella body for siblings groups, runs workshops and conferences on sibling issues throughout the UK, and produces factsheets on sibling issues for siblings, parents and professionals. It maintains a website on sibling issues, works with service providers to start local services for young siblings, sets up networks of adult siblings, and provides training for professionals.

In order to improve service delivery, a number of charities manage statutory initiatives on behalf of local statutory bodies:

- **aMAZE** in Brighton and Hove developed and manages the local register of disabled children. It works with service providers who use the information to plan which services are needed and where they should be located. It is also actively involved in the development of the local Children's Trust.
- **The Children's Society** managed the administration of the Children's Fund in Liverpool. This involved sourcing, reviewing, selecting and monitoring funding applications.

Another way of ensuring legislation is properly implemented is through the legal system. Where a local authority is failing to meet a statutory obligation, various organisations can help families take the case to tribunal or court.

- **IPSEA** and the **Disability Law Service** assist families through the legal process of obtaining services from local authorities.
- **Contact a Family** and **Carers UK** hold a wealth of information, including data about families and carers who have not received services and benefits. By collating and working through these cases they could identify particularly poor performing local authorities and develop an action plan for change.

Advocacy

Advocacy focuses on changing national legislation and policies, and local practices. Those in the best position to advocate for change are disabled children and their families. Wherever possible they should be empowered and supported to do this. There are a number of charities working to this end:

- **Circles Network** runs a free of charge Partners in Policy Making training programme for disabled adults and parents of disabled children. It aims to build community leaders and enable disabled people to influence public policy. It teaches participants about the current system and how best to work with professionals. A number of other local organisations, such as **Merseyside Partners**, also run Partners in Policy Making courses.
- **The Children's Society** works with disabled children in residential settings to provide them with a voice and communicate their needs and preferences. It ensured the involvement of disabled children and young people in the government's Quality Protects initiative — it consulted 340 disabled children and young people and produced a set of CD-Roms ('Ask Us') to communicate their message to policy-makers.
- **Contact a Family** produces a guide to local campaigning for parents' groups. The guide advises on information sources, legal rights and strategies for how to campaign and who to target. Funders wishing to support parents' groups in their advocacy efforts can channel funds through Contact a Family.

The outcomes of national lobbying are notoriously difficult to measure. Outcomes are usually the result of a series of potentially unrelated activities over a prolonged period of time. At the highest level, the outcomes are changes in public opinion, legislation and policy. Some examples of how advocacy has worked are:

- The **Council for Disabled Children (CDC)** is the umbrella body for the sector and is made up of 35 elected members representing national voluntary sector organisations, national children's organisations, specialist organisations, professional associations, parents groups and disabled people's groups. It lobbies on behalf of its members and secured the inclusion of disabled children as 'children in need' in the Children Act (1989). This ensured their legal right to services such as short breaks, assistance with equipment and housing. More recently CDC ensured the Disability Discrimination Act (2005) covered schools.

The Council for Disabled Children is the voice of the sector.

- In Northern Ireland, sustained pressure from parents and the coalition of charities **Homes Fit for Children** resulted in the abolition of the means-test for the Disability Facilities Grant in 2004.
- Representatives from **CDC, Contact a Family** and **Mencap** served on the advisory groups of the Children's NSF, the Early Support Programme family and professional packs and the Prime Ministers Strategy Unit's 'Improving Life Chances of Disabled People'. Their input on behalf of parents, professionals and disabled children has resulted in government policy incorporating these views.
- These same three organisations hired a short-term public affairs consultant in order to raise the profile of disabled children during 2004 general election manifesto time. The work led to a number of meetings with senior government officials, and increased media coverage for disabled children. These may seem like small steps, but it is this type of sustained lobbying that results in visibility of the issues and subsequent action.
- Based on its work with parents of children with impaired hearing, the **National Deaf Children's Society (NDCS)** successfully campaigned for screening of newly born babies. The campaign together with the advent of cheaper technology, led to the government roll out of screening in 2001.
- **Changing Faces** successfully campaigned to get disfigured people included in the DDA (1995). They now run courses to train employers in how to interview disfigured people and a programme of disfigurement life-skills for children, young people, adults and families.
- **Carers UK** was integral to the drafting of the Carers (Equal Opportunities) Act (2004). It campaigned for the Act and then assisted in its development.

The sector needs to increase its visibility by speaking with a single voice and developing a coordinated campaign to highlight the fact that disabled children's rights are not being upheld. A comprehensive lobbying strategy and action plan should be developed. In order to influence government and society, stronger co-operation and additional resources are needed. Donors interested in supporting this activity can do so through the **Council for Disabled Children**.



Photograph supplied by The Children's Trust

This section presents a picture of what needs to change at a societal level in order for disabled children to achieve their full potential. In addition to all of the issues described in Sections 1–3, it examines how barriers of assumption, stereotype and prejudice need to be overcome to enable disabled children and their families to live ordinary lives.

In the social model of disability, the notion of discrimination is key. Disabled people do not face disadvantage because of their impairments but experience discrimination through the way society is organised. This includes failing to make education, work, leisure and public services accessible, failing to remove barriers of assumption, stereotype and prejudice and failing to outlaw unfair treatment in our daily lives.¹³⁰ A great deal needs to be done to achieve a society where disabled children and their families are supported and enabled to live ordinary lives.

'We are invisible — we are not allowed to be part of the community. It's like we're on planet disabled and everyone else is from planet earth.'
Parent⁵⁸

The role of government

This report has shown that there is a lot to be done in order to support disabled children and their families. However, much of the necessary framework is in place. The human rights of disabled people in the UK are covered by the Human Rights Act (1998) and the Disability Discrimination Acts. These protect disabled people against discrimination from access to education, services, employment and transport. The Disability Rights Commission (DRC) is an independent body established by Parliament that monitors the workings of the DDA and promotes the rights of disabled people. The government has also set out an exciting vision of society where disabled people have full opportunities and are included as equal members of society (see Box 18). But we are not there yet. In order to achieve a situation where families with disabled children can live ordinary lives, we need to change as a society.

‘Nobody should be discriminated against for who they are.’

Disabled young person⁶

The role of the charitable sector

Some organisations of disabled people deliberately choose not to be charities or have charitable status. This is because, as proponents of the social model of disability, they believe that disabled people are not charity cases to be pitied and helped in a paternalistic way, but rather are citizens with full rights to participate in society. NPC respects this opinion. However, well-directed philanthropic resources can be used in order to further the inclusion of disabled children, so that at some point in the future, people with impairments will no longer face disabling barriers or experience discrimination. This places a responsibility on donors and funders to make sure that they direct their funds in a way that is not paternalistic, patronising or reinforcing of stereotypes and prejudice about disabled people.

Disabled people experience discrimination through the way society is organised.

Box 18: The government's vision of society in 2025

'By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society.'

This vision reflects the fact that there should be equality of opportunity for all people, irrespective of their needs. Different people will need different levels of support to access these opportunities, but the overall aim should be for disabled people to be able to take up opportunities to improve their own quality of life in a way that is comparable with non-disabled people

Prime Minister's Strategy Unit²⁹



Photograph supplied by Epic Arts

NPC believes that the organisations identified in this report meet these criteria. Supporting them will contribute towards increasing the role of disabled children in mainstream society. Many of them have disabled children and their families involved in running the organisation, setting its priorities, or driving the direction of the organisation. Others work to remove disabling barriers to ensure that disabled children are able to achieve their potential and play a larger role in society as a whole.

Research shows that disabled children and their families are subject to hurtful comments, staring and verbal or physical abuse from members of the public. For a society that considers itself to be tolerant, this is shocking. Organisations such as **RADAR, Scope, Mencap** and **Disability Alliance** campaign to protect and promote the rights of disabled people.

Increasing the profile of disabled people in the media, arts and sport and presenting positive images of disabled adults and children is necessary to overcome stereotypes, reduce ignorance and intolerance. For example, the magazine 'Disability Now' (published by **Scope**) and the National Union of Journalists have produced guidelines for journalists on how to cover disability issues in a positive way.¹³¹

The charity **Changing Faces** ran a media campaign and a poster campaign in schools to increase understanding of disfigurement. **Scope** runs public awareness campaigns and is currently seeking funds to increase the profile of disabled children in children's books. This will serve both to give disabled children positive images they can relate to and also help break down other children's prejudice. Inclusive leisure is also a great way to help non-disabled children understand that disabled children enjoy the same things as themselves (see relevant section for details on these organisations).

Presenting positive images of disabled people in the media, arts and sports can help to overcome stereotypes.



Photograph supplied by Oily Cart Theatre Company

Conclusion and recommendations

The level of services for disabled children and their families is unacceptable. There are several reasons to be concerned about this. From the perspective of efficiency, it is not ideal. Family breakdown leading to residential care of disabled children massively increases the cost to the taxpayer. Poor employment prospects of the children, as well as their parents, damages the economy, reducing tax receipts and increasing costs. Actions to improve lives of disabled children and their families can save money and improve the economy. From the perspective of social justice, it is alarming to note the poor outcomes for a disabled child compared with other children. The same can be said for families with a disabled child compared with their counterparts. From a humane perspective, the loss of potential and poor quality of life experiences available to disabled children and their families is lamentable.

The government recognises many of these problems and has launched and trumpeted many initiatives. Yet the problems remain. Perhaps current government programmes intervening throughout the life course of disabled children will bear fruit in the long run. The successful and complete implementation of 'Improving Life Chances of Disabled People', the Children's NSF and Change for Children would remove the need for most voluntary action. However, the lack of funding and persistence of problems over time must counsel caution. Even with positive government action, there is scope to do more.

The benefits from increased funding in the public, private and charitable sectors are a call to action. Results include:

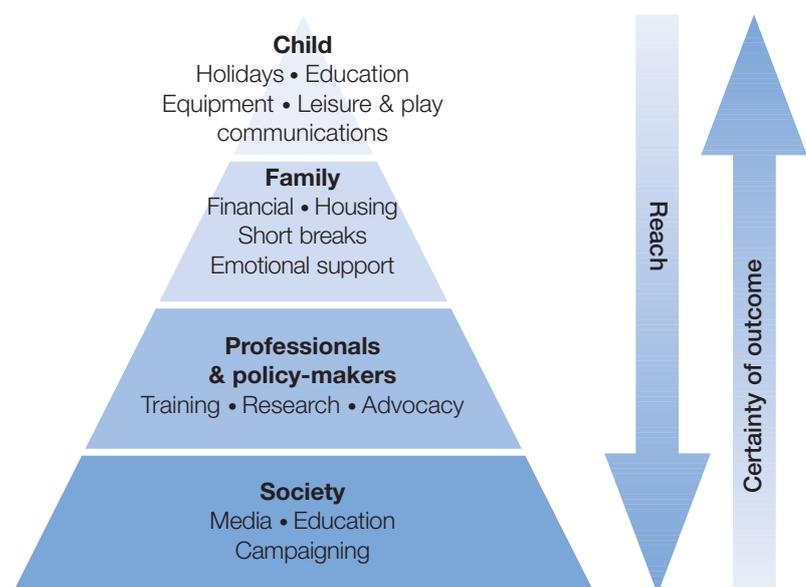
- Improving the quality of life for disabled children and their families.
- Reducing poverty levels among families with disabled children.
- Preventing family breakdowns and the subsequent placement of disabled children in residential or foster care.
- Making society more inclusive of disabled children and their families.

Many charities are involved in producing these results. Some specifically target disabled children, while others come into contact with them through more general child, carer or disability work. Most of these charities receive some funding from the government, but there is often scope to increase or extend the reach of activities using private funding. Donors and funders can have a real impact for the following reasons:

- The general level of under-funding of the sector is such that all virtually all organisations within it face funding challenges. The low priority of disabled children at a local level means new independent funding can have an impact.
- Statutory funding is limited. Local authorities develop criteria to determine which needs will be met in order to allocate resources between competing priorities. In practice, this often means catering for families when they have reached breaking point, instead of offering preventative services and support. Charities play an important role in filling some of this gap and in supporting families to lobby for improved and expanded statutory services.
- Statutory funding focuses on proven services. The charitable sector often drives innovation. Independent funding can be used to allow increased flexibility, experimentation and evaluation.

Making the choice of which charity to fund can be seen in terms of a trade-off between the different outcomes created by different organisations within the sector. This trade-off between reach and certainty is illustrated in Figure 10. The further down the triangle you move, the more children and families will benefit, but with less certainty.

Figure 10: The funding trade-off



For example, funding a holiday programme for disabled children has definite outcomes for a limited number of children who go on the holiday, — as does funding wheelchairs for children. On the other hand, funding a research centre, umbrella body or campaign has far less certain outcomes. However, over time, as these activities influence public policy and society, they should benefit a far larger number of disabled children and families.

There is no correct part of the triangle to fund. It would be wrong to always limit interventions to just one layer. To borrow terminology from the investment industry, a balanced portfolio would include charities working in each segment of the triangle. The important point is to make a more informed choice of charities.

Many donors instinctively fund the upper section of this triangle. Such donors should think about supporting a broader range of charities, shifting down the triangle. This necessarily involves organisations that are one or more steps removed from disabled children, as well as greater uncertainty over what donations achieve. However, this is compensated by the prospect of greater impact. Appetite for risk plays a role here: some funders will prefer certain outcomes. It is important to stress that intervening to help a family also benefits the child. Many services benefit both children and families at the same time. Similarly, ensuring good training for staff leads directly to better services and support for children. Restricting one’s focus to charities working only at the top of the triangle risks being overly naive and simplistic.

This begs the question of what a balanced portfolio might look like. It is difficult to generalise about charities working in any layer of the triangle. But it is possible to give indications of the type of work, costs and outcomes of charities. Earlier sections of the report have already done this. Here, the report brings together a range of data from actual charities and organisations working in this field to help donors think what a balanced portfolio might look like (see Table 6). For individual donors however, we would stress that taste and preference are important. NPC is in a position to recommend charities and structure portfolios that can improve the lives of many disabled children and their families.



Photograph supplied by Epic Arts

Table 6: Examples of activities at each layer of the triangle

Point of intervention	Activity	Cost	Benefits
Child	Placing staff and trained volunteers in local leisure facilities to support disabled children.	£42,000 can provide a full summer of local leisure and play activities for 80 disabled children.	Improved access to leisure for disabled children gives them an opportunity to make friends and gain confidence.
	Developing and performing theatre specifically for profoundly disabled children.	£3,700 for a two day workshop in a special school. £170,000 for production and touring costs to reach over 2,000 disabled children in schools and the community.	Disabled children given the opportunity to interact and communicate through the arts.
	Building circles of friends around disabled children.	£1,000 supports one child to build a circle of friends for a year.	Disabled children have friends and participate in social activities.

Table 6: continued

Point of intervention	Activity	Cost	Benefits
Family	Training parents to work with professionals and policy-makers to influence service provision.	£120,000 can pay for 30 parents or disabled adults to complete the Partners in Policy Making course.	Parents have the confidence and capacity to obtain better services for their family and influence service provision so that many others benefit.
	Providing detailed local information and advice to families with disabled children. Put them in contact with other families with disabled children for emotional support.	£150,000 can support a regional office for a year supporting a population of up to 85,000 disabled children.	Families helped to navigate complex services and deal with emotional stress.
	Providing advice and support to siblings of disabled children, their parents, and professionals.	£23,000 a year will pay for a full-time information worker to respond to enquiries from siblings, parents and professionals.	Emotional and social support needs of siblings of disabled children are better fulfilled.
	Providing free specialised legal information, advice and casework for disabled people.	£30,000 pays for an administrator. This enables the legal team to deal with more cases. £50,000 pays for a legal advisor enabling around 400 additional clients to be taken on.	Ensuring disabled children and their families get the services and benefits they are entitled to. Rulings can affect other disabled people, for example, as a result of a test case many autistic people are now eligible for a higher rate of benefit.
	Giving parents a break from round the clock care by providing holidays for disabled children.	£25,000 pays for 72 weekend residential breaks a year for disabled children.	Parents get breaks from intensive caring routines. Children make friends, develop skills and confidence.
	Professionals/policy-makers	Involving disabled people in carrying out research into disability.	£250,000 over three years covers cost of a research project into outcomes for disabled children in residential schools.
Developing a network of disabled children and supporting their involvement in policy making consultations.		£50,000 per annum can pay for cost of setting up and promoting the work of the network.	Knowledge and experience of disabled children feeds into and influences policies that affect them.

Table 6: continued

Point of intervention	Activity	Cost	Benefits
	Paying a team to develop lobbying coalition on disabled children's issues. Could include parliamentary lobbyist, media and public relations specialist.	n/d	Profile of issues affecting disabled children and their families raised on the political agenda. Public awareness and knowledge of disability improved.
	Working with local authorities to set up sibling services to provide support, reduce isolation and teach coping strategies.	£36,000 a year for three years will provide staff and project costs to work with six local authorities.	Sibling services running in local authorities providing support and information to siblings of disabled children.
Society	Inclusive arts workshops for children.	£3,600 can pay for a five day arts workshop for up to 30 disabled and non-disabled children.	Disabled children mix with their peers and gain in self-confidence. Other children learn to understand and communicate with disabled children thus overcoming prejudice and building a more inclusive society
	Project to make disabled children more visible in children's books and magazines.	£500,000 over three years for sustained action and collaboration with publishers.	Disabled children have positive role models and other children recognise disabled children as a part of society.
	All of the activities within child, family and professionals/policy-makers contribute to an impact at the societal level.		

Activities with children, families and professionals all contribute to an impact at the societal level.

The analogy of a balanced portfolio has limits because there is no common frame of reference in terms of the value of the outcome of charities' work. However, the analogy does focus attention on the possibility of supporting more than one type of charity and targeting different layers of the triangle in order to have maximum impact. For example, one might wish to support arts and play activities for disabled children, but recognise the financial problems faced by their families. Funding a charity in each of the top two levels of the triangle would be appropriate here. Alternatively, one might care about the pervasive poverty faced by many and wish to improve lobbying efforts. Local lobbying by groups of families as well as national lobbying of government would be appropriate here, leading to funding for charities in the second and third layers of the triangle. Funding a single charity can often create impact at more than one level of the triangle. For example, by funding an inclusive arts programme, one is able to simultaneously benefit the disabled children who participate as well as their non-disabled peers. Greater societal impact is achieved the more children are involved.

NPC has a number of general recommendations for donors and funders (see Box 19). NPC also found several factors that increase the likelihood of success of charities in this sector:

- Disabled children and their families should be closely involved in the organisation. They should help set the agenda and develop approaches.
- Organisations should promote an inclusive society wherever possible.
- Organisations should monitor and evaluate their work.
- Organisations should collaborate with, learn from and share information with others in the sector.

This report sets out the extent of the barriers facing disabled children and their families and highlights what the important issues are. These are really fundamental human rights, such as the right to enjoy childhood and family life. Greater awareness of the barriers for disabled children should ensure that resources are guided towards what disabled children really need: the chance to fulfil their own potential without first having to overcome disabling barriers.

Box 19: General NPC recommendations to funders

- **Unrestricted, long-term funding, including ongoing support to aid development, sustainability and capacity-building.**
- **Full cost recovery by charities — see acevo and NPC's report *Full cost recovery: A guide and toolkit on cost allocation*.**
- **Surer funding arrangements for contracted-out services — see acevo and NPC's report *Surer funding: Improving government funding of the voluntary sector*.**

Whether you are a hard-headed economist interested in financial cost-benefit analysis, a social justice campaigner concerned with the unfair deck of cards dealt to disabled children and their families, or simply a humanitarian who wants to help improve life chances, the organisations identified can make a difference. NPC actively encourages donors to fund charities in this area and it welcomes discussions with donors on specific areas of giving or the charities NPC would recommend.

NPC actively encourages donors to fund charities in this area and it welcomes discussions on recommended charities.



Photograph supplied by Choices

Appendices

Appendix 1: Summary of data on number of disabled children

Source & Year	Definition	Number of children	% of child population	Age group	Geographical focus
Reanalysis of Families and Children Study 2002, DWP ¹¹	Parents reported that child had either: (i) Long-standing illness or disability resulting in extra care needs or affecting school attendance. (ii) SEN due to physical disabilities. (iii) Intellectual disability that had significant impact on schooling.	1.2 million	10%	Under 17	Britain
Families and Children Study 2003, DWP ¹³²	Parents reported that child had a long-standing limiting illness or disability	n/d	15% of families (i.e. not % of all children)	Under 16 and 16-18 in full-time education and living at home	UK
Family Resources Survey 2002/2003, DWP ¹³	DDA definition: Long-standing limiting illness or disability affecting one or more of the activities listed in Table 1	700,000	n/d	Under 16 and 16-18 in full-time education and living at home	Britain
General Household Survey 2002, ONS ¹³³	Longstanding illness which limits activity	772,920 ^a	7% ²⁹	Age 0-15	Britain
General Household Survey 2001, ONS ¹⁰	Longstanding illness which limits activity	789,800 ^b	n/d	Age 0-15	Britain
General Household Survey 1995, ONS ¹³⁴	Longstanding illness which limits activity	345,120 ^c	n/d	Age 0-15	Britain
1991 census	Limiting longstanding illness	n/d	2.6%	Age 0-15	Britain
OPCS disability surveys 1989 ¹³⁵	Any restriction or lack of ability to perform activities considered normal for a person of similar age, which has resulted from the impairment of a structure or function of the body or mind	320,000 with one or more disability	3%	Age 0-15	Britain

^a NPC calculation: (3,431,000 x 0.04 children age 0-4) + (8,157,000 x 0.08 children age 5-15) using data presented in table 7.1 of reference¹³³

^b NPC calculation: (3,278,000 x 0.1 children age 0-4) + (8,028,000 x 0.09 children age 5-15) using data presented in table 7.2 of reference¹⁰

^c NPC calculation: (1,564,000 x 0.04 children age 0-4 + 3,532,000 x (0.08 children age 5-15) using data presented in table 7.1 of reference¹³⁴. NB: Large discrepancy between 1995 and 2001/2002 may be due to change in weighting methodology used in GHS in 1998.

Appendix 2: Relevant legislation

Legislation	Year	Relevant details
National Assistance Act	1948	Required local authorities to provide residential accommodation for elderly and disabled people. Also required that disabled people should have access to the advice and guidance, occupational activities and facilities needed to overcome communication or mobility disabilities.
Chronically Sick and Disabled Persons Act	1970	Made the provisions of the National Assistance Act (1948) S29 mandatory rather than discretionary.
Local Authority Social Services Act	1970	Created Social Services Authorities. Social service departments are permitted to undertake certain functions under this Act and the list is regularly updated. This includes needs assistance and provision or purchasing of care packages for disabled children.
Education Act	1981	Duty on LEAs to include pupils with special educational needs into mainstream education where appropriate (where the needs of the child are properly met, other children's education is not adversely affected, resources are efficiently used, and parents are in agreement).
Health and Social Services and Social Security Adjudication Act	1983	Under provisions within this Act, local authorities can charge for both community care services and equipment where the recipient of these can afford to repay them.
Disabled Persons (Services, Consultation and Representation) Act	1986	Right for disabled persons and their carers to request an assessment of their needs. Only after an assessment of needs has been undertaken by social services that a decision is made - by social services - as to the quantum of service that should be provided. Requires the local authority to take account of the ability of a carer to provide or continue to provide care when deciding what services to provide to the disabled person.
The Children Act	1989	Broad civil liberty provisions, in particular for disabled children or children in need. Includes 'the best interest principle' and requires local authorities to provide services for 'children in need' and their families, including daycare, respite, assistance with equipment, housing and general support. Where there is a disabled child the local authority has an obligation to assist the family if they need help in bringing up their child.
National Health Service and Community Care Act	1990	Transferred budgets to local authorities.
Education Act	1993	Duty on LEAs to identify and assess children with special educational needs. Qualified duty to secure education in 'ordinary school' (same conditions as 1981 Act).
UNESCO Salamanca Statement	1994	Encourages inclusion in schools.
Disability Discrimination Act (DDA)	1995	Protects all disabled people from 'less favourable treatment' in access to education, services, employment and transport.

Appendix 2: continued

Legislation	Year	Relevant details
Carers (Recognition and Services) Act	1995	Requires Social Service Authorities to assess the needs of the carer as a separate activity. Recognises the importance of carers as the main providers of social care.
Community Care (Direct Payments) Act	1996	Gave councils the power to provide Direct Payments to individuals who needed community care services.
Education Act	1996	Part 4 outlines the duty LEAs have to identify, assess and provide for children requiring statements of SEN. This duty covers children from the age of two, and before that if a child is identified by his or her parents, the child health services or social services as having special needs.
Human Rights Act	1998	European Convention on Human Rights incorporated into British domestic law through this Act. It states 'no one shall be subjected to torture or to inhuman or degrading treatment or punishment'.
Direct Payment Act	1998	Places a duty on local authorities, in certain circumstances, to make Direct Payments to enable people to obtain for themselves the services that they are assessed as needing.
Care Standards Act	2000	Established the National Care Standards Commission as the regulator. Contains prescriptive standards aimed at every detail of the care industry. Also stipulates the use of the Criminal Records Bureau (CRB).
Carers (Services and Representation) Act	2000	Gives carers the right to an assessment of their needs by the local authority when it carries out an assessment of the person cared for in respect of community care services (although not a right to services).
Carers and Disabled Children Act	2000	Provides a new right for a carer to be assessed even if the disabled person has not been assessed. Services to carers are not defined in the Act, and the local authority may provide any services which, in their view, will support the carer in their caring role. In certain cases the Act allows carers and disabled children to receive direct payment in lieu of the provision of services, to receive vouchers for respite care, as well as giving them further rights to assistants and services. Social services can charge for services provided under this Act.
Health and Social Care Act	2001	Gave councils the duty (rather than the power) to make Direct Payments instead of providing direct services. This came into effect on 1 April 2003.
Special Educational Needs and Disability Act (SENDA)	2001	Removes two out of three qualifications for placement in mainstream school. LEAs must now include children with SEN unless this prejudices the education of other children and there are no reasonable steps which could be taken to prevent this prejudice.
Education Act	2002	Encourages schools to provide and host a range of services, including childcare, through the new Extended Schools programme.

Appendix 2: continued

Legislation	Year	Relevant details
Children Act	2004	<p>Building on 'Every Child Matters' sets out reforms of children's services including:</p> <ul style="list-style-type: none"> • Children's Commissioner for England. • Duty on local authorities to promote co-operation between agencies (through Children's Trusts which bring together health, education and social services within a single agency and will enable multi-agency working). • Duty on key agencies to safeguard children. • Requirement on local authorities to appoint Director of Children's Services and designate Lead Members. • Integrated inspection framework and joint area reviews.
Carers (Equal Opportunities) Act	2004	<p>Seeks to give carers more choice and better opportunities to lead a more fulfilling life by ensuring that carers receive information about their rights under the 2000 Act. It also ensures that carers' assessments consider leisure, training and work activities, and provides for co-operation between local authorities and other bodies, including housing, education and health, in relation to the planning and provision of community care services that are relevant to carers.</p>
Disability Discrimination Act	2005	<p>Amends the DDA of 1995 and place a new duty on the public sector 'to promote disability equality' (this parallels the Race Relations Amendment Act). It also brings people with HIV, cancer and multiple sclerosis into scope.</p>

Appendix 3: Recent government initiatives

Initiative	Description
Publications	
<p>'Improving the Life Chances of Disabled People'</p> <p>January 2005</p> <p>Prime Minister's Strategy Unit</p>	<p>This report, which has been agreed as government policy, makes recommendations across four key areas:</p> <ul style="list-style-type: none"> • Independent living • Early years and family support • Transition to adulthood • Employment
<p>'Choice for Parents, the Best Start for Children'</p> <p>December 2004</p> <p>HM Treasury</p>	<p>The government's Ten Year Strategy for early years and childcare was published alongside the Pre Budget Report (PBR). Its key themes were:</p> <ul style="list-style-type: none"> • Choice and Flexibility • Availability • Quality • Affordability
<p>Every Child Matters: Change for Children</p> <p>December 2004</p> <p>DfES</p>	<p>Sets out how the five outcomes for children have been developed into a national framework for 150 local programmes of change. The framework aims to inform policy development, assessment, inspection and delivery at the national and local level. A detailed Outcomes Framework has been developed with the inspectorates to inform monitoring of progress towards priority targets.</p>
<p>National Service Framework for Children, Young People and Maternity Services</p> <p>September 2004</p> <p>DoH</p>	<p>Sets out national standards for the first time for children's health and social care. It is a ten-year programme for improvement in children's health and well-being to be achieved through eight standards. It is intended to lead to a cultural shift, resulting in services being designed and delivered around the needs of children and families.</p>
<p>Child Poverty Review</p> <p>July 2004</p> <p>HM Treasury</p>	<p>Examines the welfare reform and public service changes necessary to advance towards the goal of halving child poverty by 2010 and eradicating it by 2020. Sets out the key measures to reduce child poverty in the medium to long-term through:</p> <ul style="list-style-type: none"> • Improving poor children's life chances. • Helping parents who can work into work. • Providing financial support and tackling material deprivation. <p>'Child poverty accord: supporting local authorities in their contribution to the child poverty agenda' published in November 2004 (out of Child Poverty Bill) sets out how the Treasury, LGA, DWP and DfES intend to work together to tackle child poverty</p>

Appendix 3: continued

Initiative	Description
<p>'Removing Barriers to Achievement'</p> <p>Special Educational Needs (SEN) Strategy</p> <p>February 2004</p> <p>DfES</p>	<p>Sets out the Government's vision for the education of children with special educational needs and disabilities. Four key areas:</p> <ul style="list-style-type: none"> • Early intervention. • Removing barriers to learning – by embedding inclusive practice to every school and early years setting. • Raising expectations and achievement – by developing teachers' skills and strategies for meeting the needs of children with SEN. • Delivering improvements in partnership.
<p>'Every Child Matters'</p> <p>September 2003</p> <p>Green Paper</p> <p>DfES</p>	<p>Building on the recommendations of the Laming Inquiry the green paper sets out policies to protect children and to maximize the potential of all children. Sets out the five key outcomes for children and young people (see Section 3 for the five outcomes). Focuses on four main areas:</p> <ul style="list-style-type: none"> • Supporting parents and carers. • Early intervention and effective protection. • Accountability and integration – locally, regionally and nationally. • Workforce reform. <p>Aims to ensure that every child has the chance to fulfil their potential by reducing levels of educational failure, ill health, substance misuse, teenage pregnancy, abuse and neglect, crime and anti-social behaviour among children and young people. Led to the Children Act (2004) and Change for Children Programme.</p>
<p>'Services for disabled children. A review of services for disabled children and their families'</p> <p>September 2003</p> <p>Audit Commission</p>	<p>In-depth review of services which resulted in a vision of effective services with four components:</p> <ul style="list-style-type: none"> • Services meet families' needs. • Families participate in everyday life. • Services recognise that children grow and move on. • Services recognise, recruit and develop the right people.
<p>'Beyond 2004 – A DCMS Framework for Action on Disability'</p> <p>July 2003</p> <p>DCMS</p>	<p>The framework sets out what the Department for Culture Media and Sport, its Sponsored Bodies and wider sectors can do to contribute to the goal of full equality for disabled people.</p>
<p>'Together from the start'</p> <p>May 2003</p> <p>DoH, DfES</p>	<p>Government guidance which recognises that when children have special needs and disabilities, it is important that these are identified at an early stage and that identification leads directly to effective early intervention and support for children and families. For agencies working to assist disabled children and their families from birth to age two.</p>
<p>The Victoria Climbié Inquiry</p> <p>January 2003</p> <p>Lord Laming Inquiry</p>	<p>A public inquiry was set up following the death of Victoria Climbié in February 2000 and the subsequent murder conviction of her carers in January 2001. The report sets out recommendations to address the root causes of the failure to prevent Victoria's death.</p>

Appendix 3: continued

Initiative	Description
<p>'Valuing People: A Strategy for Learning Disability for the 21st century'</p> <p>March 2001</p> <p>White Paper</p> <p>DoH</p>	<p>States that people with learning disabilities should receive services to give them 'fulfilling lives'. Services should be based on four principles:</p> <ul style="list-style-type: none"> • Choice • Inclusion • Legal and civil rights • Independence <p>Introduced Learning Disability Partnership Boards in every local area which include representation of family carers and people with learning disabilities.</p>
<p>Framework for the Assessment of Children in Need</p> <p>April 2000</p> <p>DoH</p>	<p>Sets out the arrangements for deciding on the support a family receives. The framework provides a systematic way of analysing, understanding and recording what is happening to children and young people within their families and the wider context of the community in which they live.</p> <p>It is currently being revised and the government is proposing to introduce a Common Assessment Framework with the aim of reducing the number of assessments faced by children and their families by combining the assessments of the various agencies into a single system.</p>
<p>'Working Together to Safeguard Children'</p> <p>December 1999</p> <p>DoH, DfES, Home Office</p>	<p>Sets out how all agencies and professionals should work together to promote children's welfare and protect them from abuse and neglect.</p> <p>Recognises that disabled children are at an increased risk of abuse and sets out measures to address this.</p>
<p>'Caring about Carers'</p> <p>January 1999</p> <p>DoH</p>	<p>Sets out how the government will acknowledge the value of carers in the community by offering information, support and care to the carers. Includes plans for special provision to help carers in employment and young carers as well as plans for legislation and financial measures.</p>

Appendix 3: continued

Initiative	Description
Programmes	
<p>Sure Start 1999 - current</p>	<p>Government programme which aims to achieve better outcomes for children, parents and communities by:</p> <ul style="list-style-type: none"> • Increasing the availability of childcare for all children. • Improving health and emotional development for young children. • Supporting parents. <p>524 Sure Start Local Programmes offer services to 410,000 children under four years of age – 29% of all poor children under four across England. Expenditure of about £200 million a year. Sure Start aims to identify pre-school children with special educational needs and provide early intervention and support. The general Sure Start grants include a strand for SEN and Disability.</p> <p>Children’s Centres provide families with pre-school children in disadvantaged areas integrated early education and childcare, family support, health and advice on employment and training opportunities. The ten year childcare strategy sets out the aim of having 3,500 children’s centres by 2010.</p> <p>Extended Schools refer to primary and secondary schools providing study support, family and lifelong learning, parenting support, childcare, some health and social care services, access to ICT facilities and access to sports and arts facilities. Beyond this, the government wants primary schools to develop an 8am - 6pm wraparound childcare offer. The ‘Five Year Strategy for Children and Learners’ (July 2004) sets out the Government’s vision that all schools will become extended schools over time.</p>
<p>Early Support Programme 2002 – current</p>	<p>Programme involving the DfES, Sure Start and the DoH. Its purpose is to improve the delivery of services to disabled children under three and their families. Promotes service development in partnership with education, health and social services, voluntary organisations and service users themselves. Early Support is putting into practice the principles outlined in ‘Together from the start’.</p> <p>Developed comprehensive toolkits for professionals and families which the government has committed to spreading to all local authorities and Children’s Trusts. The DfES has provided £13 million to support the development of services in 2002-2006.</p>
<p>Quality Protects April 1999 - March 2004</p>	<p>A children’s services funding initiative (£885 million over five years) with specific funds for services for disabled children and their families (£60 million over the five years). The main objective for disabled children was to ensure that they gain maximum life chance benefits from educational opportunities, health care and social care, while living with their families or other appropriate settings in the community where their assessed needs are adequately met and reviewed.</p>
<p>Connexions</p>	<p>Support service available to all 13-19 year olds and to 14-25 year olds with learning disabilities in England. The service aims to provide integrated advice, guidance and access to personal development opportunities for this group and to help them make a smooth transition to adulthood and working life. Connexions can assist with any issue of concern including careers, learning, health, housing, rights, relationships, and finances. Young people can access the service through local Connexions Partnerships.</p>

Appendix 3: continued

Initiative	Description
Funds	
Children's Fund	<p>Programme to stimulate multi-agency working and partnership between voluntary, statutory and community sectors and young people. Aimed at children aged 5-13 and connects government initiatives that address social exclusion amongst children/young people and their families. Funding provided centrally but administered locally. Funding is based on the number of children in poverty in each area and the waves were phased so that areas of most need received funding first.</p> <p>Largest national programme being delivered by the Children and Young People's Unit. Initial allocation of £350 million from Spending Review 2000; allocated £450 million from the Spending Review 2002.</p>
Carers Grant DoH	<p>Introduced in 1999, the grant forms part of the Government's strategy for carers, set out in 'Caring about Carers'. It is designed to stimulate diversity and flexibility in provision of breaks for carers or direct services to carers to support them in their caring role. In 2005/2006 the Carers Grant will increase by £60 million to £185 million and will continue at this level until 2008.</p>
Learning Disabilities Development Fund (LDDF)	<p>Fund to support the implementation of 'Valuing People' which sets out a programme to improve services for people with learning disabilities. £41.6 million to be distributed between the 303 PCTs in 2005/2006 with an additional £700,000 announced in March 2005.</p>
Early Years and Childcare Grant	<p>One component of the Early Years and Childcare Grant allocated to local authorities is the 'SEN and Disability Development Grant'. This strand brings together three previous strands of funding — SENCO training, disability childcare and the low incidence disability grant — into a single ring fenced budget. The new grant has three strands:</p> <ul style="list-style-type: none"> • SENCO training. • Early Intervention. • SEN/Disability and childcare. <p>It is intended to be flexible and it will be possible to move resources from one element to another as long as some basic conditions are met. The SEN and Disability Strand of the Grant was £18 million in 2003/2004.</p>
Local Network Fund for Children and Young People DfES	<p>The aim of this fund is to help children achieve their potential by investing in the activities of local community and voluntary groups working for and with children and young people aged 0-19. It was set up for three years with a total budget of £70 million. The 2002 spending review extended the Fund for a further two years until March 2006 with an additional £80 million. Grants are made under four themes: aspirations and experiences, economic disadvantage, Isolation and access, and, children's voices.</p>
Direct Payments Development Fund	<p>£9 million over three years targeted at national, regional and local voluntary organisations, in partnership with local councils, to enable them to play a significant role in the development and promotion of Direct Payments.</p>

Appendix 3: continued

Initiative	Description
Parenting Fund DfES	The 2002 Spending Review announced the creation of the Parenting Fund, worth £25 million over three years, to develop parenting support. It will go directly to the voluntary and community sector to support parenting and parenting organisations. The government intends to put supporting parents and carers at the heart of its approach to improving children's lives, where support is needed or wanted.
Safeguarding Children and Supporting Families DfES	The aim of this fund is to strengthen and further develop the partnership between the DfES and the voluntary and community sector. Funding supports innovative projects of national significance that complement statutory services, and help secure and promote high-quality children's social care in England.
Strengthening Families DfES	The aim of this programme is to support and develop activities which enable families to get access to information, help and advice. The programme has been formed by the merger of the Marriage and Relationship Support (MARS) and Family Support (FSG) grant programmes, following the creation of the DfES Children, Young People and Families Directorate.

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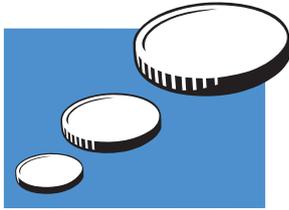
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