

ABOUT FAMILIES WITH DISABLED CHILDREN - UK

contact a family
for families with disabled children
incorporating
The Lady Hoare Trust



www.cafamily.org.uk

Helpline 0808 808 3555 interpreters in over 100 languages via



Lãnguagê Liñè

Introduction and some statistics

This factsheet aims to give an insight into the common needs and problems experienced by disabled children and their families. Professionals and others will therefore have a greater understanding of what is involved in caring for a disabled child or young person and what is needed in terms of services, financial help, and emotional support that benefits the whole family helping them to live ordinary lives.

It is worth remembering as you read this factsheet that despite the challenges, financial consequences and acute lack of services to support disabled children and their families, parents give their time willingly; to them their child remains very special and much loved.

'As soon as you see her smile, everything that you felt you were going to give up just goes out the window. As soon as she smiles, you know she's happy.'

“ She was our baby. She was our first. To us, whether there was something wrong or not, she was still a baby. She still needed us, and so we just got on with it. ”

We know from the latest analysis of the 2001 census that 7% of all children are disabled. This means there are 770,000 disabled children in the UK. That equates to one child in 20¹. It is estimated that around 14% of the 6 million carers in the UK look after a disabled child².

The population of disabled children has changed significantly since the early 1980s³. In addition to increases in autistic spectrum disorders, due to medical and technological advances more babies and children are surviving, living longer and with more complex needs.

There is substantial existing information on childhood disability that provides valuable insights into the lives and circumstances of disabled children and those closest to them. However, there is an absence of reliable current national data on prevalence, trends and the socio-demographic characteristics of disabled children and their households. Due to how data is collected, different definitions of disability and overlaps between data sources, our understanding of this important group within the population is limited. The limitations of national data on disabled children and their families are widely recognised.

The most comprehensive national disability surveys were undertaken by the Office of Population Censuses and Surveys (OPCS) between 1985 and 1989 and are consequently out-of-date. Gordon et al (2000) later undertook a re-analysis of the OPCS data and, for some purposes, policy-makers and researchers still tend to rely on this as the most robust national data currently available. The Family Fund database is

also one of the most frequently used and highly regarded national sources of information on disabled children and their families. More recently, the Department for Work and Pensions' (DWP) Family Resources Survey (FRS) has collected national data on disabled children (DWP 2004).

The question of defining 'disability' remains a matter of debate. There is a helpful article on this issue, including the contrasting medical model and social model of disability by Tom Hutchinson⁴. The use of language and 'politically correct' terminology is constantly being modified. It is important to recognise this but use of non-labelling words with positive connotations is more helpful. Parents themselves may also not see their child as disabled.

Contents

Key facts	page 4	Short term breaks	page 11
Aspects of caring	page 5	Inclusion	page 12
Financial considerations	page 6	Key legislation and policy	page 14
Working and caring	page 7	Further information and useful contacts	page 16
Services and support	page 8		



Key facts

Over **90% of disabled children** live at home and are supported by their families.

55% of families with a disabled child live in, or on the margins of, poverty.

Only **1 in 13 families** get services from their local social services.

Disabled children are **13 times** more likely to be excluded from school.

A **quarter of families** with disabled children say services are poor or lack co-ordination.

Three quarters of families with a disabled child live in an unsuitable home.

Only 16% of mothers with disabled children are in paid employment (compared to 61% of other).

A **greater proportion** of households with disabled children have a lone parent.

4 | About families with disabled children | www.cafamily.org.uk



Aspects of caring

The majority of disabled children are brought up at home and are dependent upon family members to meet their basic care and treatment needs:

- ☞ Eating/drinking - these may include specialist food requirements;
- ☞ Toileting;
- ☞ Bathing;
- ☞ Communication - includes speech difficulties and/or ability to express moods/needs;
- ☞ Mobility - some children cannot walk independently or sit up without assistance;
- ☞ Maintenance of medical regimes - often several times a day;
- ☞ Physiotherapy.

Uncoordinated meetings and appointments with consultants, health visitors, occupational therapists, speech

therapists, clinical psychologists, educational psychologists and a host of other professional workers act as a regular drain upon time and energy for both the parent and the child.

Many children with disabilities and/or health conditions are diagnosed as having challenging behaviour. Exactly how challenging their behaviour is may vary widely from night time disturbances to extensive damage to the family home and, in extreme cases, self-injury. Challenging behaviour, in all its forms, can be an unrelenting source of stress and upset for the whole family.

Research also shows that due to the greater and more complex care needs of disabled children finding time for other non-disabled members of the family is more difficult. It may adversely affect a parent's social life; general fatigue and difficulty in finding suitable childcare or sitters may prevent the parent from socialising or working outside the home. Friends and even family members may no longer wish to visit the parent at home.

Caring for more than one disabled child

An analysis of the Family Fund database, which records details of applications for grants from families with severely disabled children, has estimated that about 7,000 families in the UK have more than one disabled child with severe impairments, representing well over 15,000 children. It also shows that these families have additional disadvantages compared to those families caring for one disabled child, including not working and being reliant on benefits, as well as an increased likelihood of lone parenthood and parental ill-health or impairment. The survey also showed that only one 1 in 24 of the families surveyed were receiving help from social services⁵.

Financial considerations

Families with a disabled child are also adversely affected by the additional financial costs of bringing up a disabled child and reduced earning capacity associated with caring:

It costs, on average, three times more to bring up a disabled child than a non-disabled child. These additional costs faced by families with disabled children don't include the social and emotional costs incurred⁶.

Due to reduced earning capacity families feel they cannot afford the 'treats' that other parents may provide. Parents often report going into debt to meet their child's basic needs⁷.

Financial assistance is available in the form of benefits and tax credits. Some benefits may be payable because the child is disabled. The most common is Disability Living Allowance (DLA). It is usually paid every four weeks and is

non means-tested. DLA has two parts – the care component and the mobility component and either or both parts can be claimed. If a child receives the middle or highest rate of DLA care component their parent, may also be entitled to receive Carers Allowance. There are also benefits for families on a low income such as Income Support and others such as Working Tax Credit that helps working families with children.

Many families with disabled children are not claiming the benefits they are entitled to⁸. The benefits system is complex, with eligibility for one benefit often dependent upon eligibility for another, and parents find it difficult to navigate their way through. Parents are busy people and sometimes struggle to find the time and energy to fill out the forms.

Black and minority ethnic (BME) families with disabled children

These families are more likely to experience poverty, worklessness or low status employment and less likely to report impairment than white families.

They have lower take up of services and often feel less well informed or able to access the system. Research carried out in 1999⁹ found that fewer families from these communities were receiving disability benefits compared to white families with children with similar degrees of disability, and were less likely to be awarded Disability Living Allowance at the higher rate⁹. Poor interpreting services and limited availability of translated materials also makes access to information difficult.

It is important that BME families with disabled children are able to access affordable, high quality and culturally appropriate services to help overcome social exclusion in the short and long term.

Working and caring

Parents of disabled children are less likely than other parents to be in employment and this is particularly the case for mothers¹⁰. Lack of opportunity to work can result in personal and financial hardship for parents. A range of factors influence parent's ability to gain work outside the home, including:

- ☞ Finding affordable, appropriate and quality alternative care e.g. childcare;
- ☞ A flexible employer or manager who has a positive attitude to caring responsibilities;
- ☞ Earning enough to cover costs, including loss of benefits;
- ☞ Low confidence, and access to training;
- ☞ Health problems associated with caring.

Did you know about? Carers Assessments

The Carers (Equal Opportunities) Act 2004 seeks to give those with caring responsibilities the opportunities that those without caring opportunities take for granted. When conducting a carers assessment parents should be asked about their work situation, or wishes to return to work, opportunities to study or participation in leisure activities. This should be taken into account when planning the care package.

Direct Payments

Following implementation of the Health and Social Care Act 2012, direct payments must be offered to parents of disabled children, giving greater choice and flexibility in how they receive services. Direct payments are cash payments in lieu of social services.

For further information you may find our factsheet *'Working and caring for a disabled child'* useful.





Services and professional support

A report by the Audit Commission in 2003¹¹ found that there was a lottery of provision, inadequate planning, confusing eligibility criteria, and that families were subject to long waits and had to 'jump through hoops' to get support.

The needs of disabled children and their families cross traditional service and professional boundaries. Limited joint planning and working between health, education, and social services along with a lack of co-ordination with housing, transport, leisure and childcare departments means what should be provided and what is provided are not always the same. A lack of funding is also a principal factor in the quality of services families receive.

Lack of consistency and communication were key findings of research into housing and disabled children¹², which found that:

- ☞ Families with disabled children had far greater problems with housing than other families, and the difficulties with housing were across all types of disability;
- ☞ Families often dealt with housing difficulties by moving, rather than adapting the home;
- ☞ Most frequent on a list of housing difficulties were lack of space, the condition of the housing and difficulties with access;
- ☞ More than one third of families interviewed had difficulties with the location of their home, due to safety or problems with neighbours;
- ☞ Very few families had had help or support from statutory agencies.

The development of children's trusts, the implementation of the children's National Service Framework (NSF), the Early Support programme and increased involvement of parents and disabled children in the planning and commissioning process aims to improve the design and delivery of services.








Transition into adulthood

Leaving school and moving into adulthood is a challenging time for disabled young people and their parents. Many parents feel anxious at this time, predicting poor services or a possible lack of choice for their children. The support they may have enjoyed through local parents' groups or local children's services may seem to be about to fade away. For these reasons it is vital that parents, their children and professionals plan for transition as early as possible.

Did you know?

Children's centres are at the heart of the government's *Every Child Matters* agenda in England. They are based on the concept that providing high-quality integrated services (health, education, family support and childcare), leads to positive outcomes for children, families and their communities. In Wales this takes the form of integrated children's centres, whilst some areas in Scotland have children and family centres offering a range of services including childcare. By 2010, in England, the intention is to have a Sure Start children's centre in every community serving children and families from the antenatal period, through to starting school.




Children centres have the potential to provide exactly the sort of services and support families with disabled children need:

-  Parental outreach and family support services (e.g. training managing sleep problems, challenging behaviour etc.);
-  Portage (home-visiting services);
-  Key workers;
-  Child and family health services, including therapy services (physiotherapy, speech & language etc);
-  Information, advice, counselling and support;
-  Good quality childcare;
-  Links to Jobcentre plus, children's information services (CIS) and extended school services.









Information needs

Families with disabled children need information in an accessible and usable form. They are more likely to make use of material that is geared to events and circumstances that are a priority to them at particular points e.g. at transition. When a child has a severe disability or high levels of need, the parents require a single point of contact to provide information, to help obtain the services, and to assist with advocacy. Studies of key workers consistently report positive effects on relationships with services, fewer unmet needs and greater family well-being.

In regard to specific subjects, parents wanted information on¹³:

-  Benefit entitlements;
-  A disability or condition;
-  Different forms of childcare available and short break provision;

“It’s frustrating trying to understand what all the professionals do and keeping track of all the different appointments, telling our story over and over.”

-  Leisure activities;
-  Support groups;
-  Knowing your rights and how to complain;
-  Support for the whole family;
-  Help in dealing with behavioural and emotional problems;
-  Housing options and adaptations;
-  Opportunities when young people leave children’s services;
-  Friendships, relationships and sexuality.

Short-term breaks

These are highly valued services that research¹⁴ shows provides an opportunity:

- For children to experience new activities, experiences and relationships in the community;
- For parents to take a break and spend time with other non disabled siblings

Despite the fact access to a regular break is one of the most requested support services and also the benefits in terms of reducing stress and family breakdown, the latest UK survey¹⁵ on short break schemes found:

- Huge numbers of disabled children are still waiting for short break services, many waiting years;
- Some children, such as those with autistic spectrum disorders, challenging behaviour or those

with complex health needs, have to wait longer than others;

- The biggest group of children waiting longest is teenage boys with autistic spectrum disorders or challenging behaviour.

The report also highlighted the barriers services faced in recruiting paid carers, the quality of services and lack of funding.

Other research¹⁶ focused on black disabled children and their families found that:

- Over the last ten years take-up of short breaks has not significantly increased, with particular unmet need amongst South Asian families. In addition a high proportion of families using short breaks are using institutional rather than family-based care, far higher than in white communities;

// The biggest group of children waiting longest is teenage boys with autistic spectrum disorders or challenging behaviour.//

- Home-based services, such as sitting services, are very popular with families;
- Services do not adequately accommodate the needs of families from minority ethnic communities;
- Lack of information was a main barrier to the use of services.

Inclusion

Disabled children should be fully included and be able to participate in their community alongside their peers. However they are often excluded from mainstream services due to factors such as a negative attitudes, physical barriers, and poorly trained staff.

Research focusing on young disabled people and their experiences of inclusive leisure¹⁷ found that:

- Friendship and fun were the most important aspects of inclusive leisure for young disabled people;
- Lack of appropriate support, e.g. transport and interpreting, was a key barrier for young disabled people wanting to access inclusive leisure;
- Young disabled people valued the opportunity to be involved in mainstream activities, but also wanted to meet other young disabled people to share experiences.

Another benefit for young people can be seen within research on inclusive education¹⁸, which found that:

- Children with disabilities benefit educationally from inclusive education, whilst pupils without disabilities also do as well or better within an inclusive setting;
- Peer acceptance is seen in an inclusive setting, although more so in primary than secondary education;
- Pupils, parents and teachers have positive experiences of inclusive education.

Families' experiences

The wealth of research on disabled children and their families has been drawn together by the Joseph Rowntree Foundation and identified the following key issues¹⁹:

- Listening to disabled children and young people;

// Children with disabilities benefit educationally from inclusive education, whilst pupils without disabilities also do as well or better within an inclusive setting // ¹⁸

- Providing information and advice;
- Positive attitudes and a co-ordinated approach;
- Flexible support services which are tailored to individual children's and families' needs;
- Having more money;
- Measuring the actions of all statutory and voluntary agencies against the human rights of disabled children.

Support groups

Within the disability sector a wide range of voluntary organisations and informal local support groups exist, some relating to specific conditions, e.g. spina bifida, cerebral palsy and some following a broader brief such as learning disabilities. Groups may operate at a local or national level. Research by Contact a Family Wales²⁰ found that these groups offered a variety of services including:

- ☞ Play and leisure facilities;
- ☞ Mutual support;
- ☞ Information;
- ☞ Training.

For many parents, finding a group can be the first step to reducing isolation and discovering more about what services and treatments are available. Unfortunately, many parents are unaware that such groups exist, missing out on a vital source of support. Contact a Family produce 'group action pack' guides on

'Starting a Local Group' and *'Starting a National Group'*.

Contact a Family also operates a web based linking service www.makingcontact.org whereby a parent can register to be contacted by other families affected by a particular condition by e-mail, from across the world.

Campaigning

A number of umbrella bodies such as the Council for Disabled Children, the Special Education Consortium, Children in Scotland, Children in Wales and organisations like Contact a Family and MENCAP are focused on getting a better deal for families with disabled children. They bring the views and experiences of families to the attention of government, MPs, the media and the wider community. By raising the profile of disabled children and their families this leads to improvements in national and local policies, legislation and more sensitive practice amongst professionals.



Key legislation and policy

There is a large amount of legislation and policy relevant to disabled children and their parents. The legal framework differs across the UK and in this section we provide only a brief overview. For more information about the legislation in the nations please ring:

Contact a Family Scotland,

Tel: **0131 475 2608**

Contact a Family Cymru,

Tel: **029 2049 8001**

Contact a Family Northern Ireland,

Tel: **028 9262 7552**

The Children Act 1989 (s17) means social services departments in England and Wales have a duty to assess the needs of a child with a disability. This process consists of gathering information, making a decision on service provision (often using eligibility criteria) and preparing and implementing a care plan. Under this Act and the *Chronically Sick and Disabled Persons Act 1970* local authorities must ensure a range of support services are available such as:

- Advice and counselling;

- Help with transport;
- Home help (including laundry service);
- Cultural, social, recreational or occupational activities;
- Daycare;
- After-school and holiday provision;
- Help with holidays;
- Long stay accommodation for children who cannot live at home;
- Short-term care to give families a break;
- Financial help by grant or loan²¹.

The Children (Northern Ireland) Order 1995 and *The Children (Scotland) Act 1995* have similar provisions and principles to *The Children Act 1989*.

The Children Act 2004 provides a legislative spine for the wider strategy for improving children's lives. This covers the universal services which every child accesses, and more targeted services for those with additional needs. The overall aim is to encourage integrated planning,

commissioning and delivery of services. There are some specific laws that relate to carers including employment rights such as the *Employment Act 2002* which gave parents of disabled children under 18 the right to request flexible working arrangements.

Others Acts give parents and carers the right to an assessment of their own needs such as the *Carers and Disabled Children Act 2000*, *Community Care and Health (Scotland) Act 2002* and the *Carers and Direct Payments Act (Northern Ireland) 2002*. These Acts also make provision for direct payments to be made to parents with disabled children where they have been assessed as needing a service.

The Carers (Equal Opportunities) Act 2004 places a statutory duty on social services departments to inform carers of their right to an assessment. It also aims to promote better joint working between councils and the health service to ensure support for carers is delivered in a co-ordinated manner.

The Childcare Act 2006 places a duty on local authorities to provide childcare for parents with disabled children up to 18 and improve the information on childhood services available to them.

The Disability Discrimination Act (DDA) 1995 aims to end the discrimination that many disabled people face. This Act gives disabled people rights in the areas of:

- Employment
- Education
- Access to goods, facilities and services
- Transport

From 1 October 2004, Part 3 of the DDA 1995 has required service providers to take reasonable steps to tackle physical features that act as a barrier to disabled people who want to access their services.

In April 2005 a new *Disability Discrimination Act* was passed by Parliament, which amends or extends

existing provisions in the DDA 1995, such as requiring public bodies to promote equality of opportunity for disabled people.

The Special Educational Needs and Disability Act 2001 amended the *Disability Discrimination Act 1995 (DDA)* to make it unlawful for education providers to discriminate against disabled pupils, and adult learners, and to ensure disabled people are not disadvantaged in comparison to people who are not disabled.

Policy and guidance

Improving life chances of disabled people, 2004

<http://tinyurl.com/grrzx>

Health White Paper: Our health, our care, our say: a new direction for community services, 2006

<http://tinyurl.com/c8ne2>

National Service Framework for Children, Young People and Maternity Services,

2004 - For **England**

<http://tinyurl.com/rr4tg>

For **Wales**

<http://tinyurl.com/mvmyr>

Removing barriers to achievement: the government strategy for SEN, 2004

<http://tinyurl.com/pmuvr>

Extended Schools: providing opportunities and services for all, 2005

<http://tinyurl.com/nfwp8>

Children's centres practice guidance, 2005

<http://tinyurl.com/rtt5d>

Further information and useful contacts

Useful Publications

A Special Child in the Family: Living With Your Sick or Disabled Child.

Diana Kimpton. ISBN 184294 1151

<http://www.dianakimpton.co.uk/specialchild.htm>

Special Education Handbook: The Law on children with special educational needs Advisory Centre for Education. 2005. ISBN 1 870672 72313

Right From The Start: Looking at diagnosis and disclosure - parents describe how they found out about their child's disability.

SCOPE. 1999. ISBN 0 946 828 38 5.

<http://www.rightfromthestart.org.uk>

No Ordinary Life - The support needs of families caring for children and adults with profound and multiple learning disabilities. Mencap. 2001.

http://www.mencap.org.uk/download/no_ordinary_life.pdf

Child Health in the Community: A

guide to good practice.

Department of Health, 1996

<http://tinyurl.com/merqo> and <http://www.dh.gov.uk>

Moving pictures: Realities of voluntary action.

Duncan Scott, Pete Alcock, Lynne Russell and Rob Macmillan. Policy Press. 2000. ISBN 1 86134 233 0

<http://www.jrf.org.uk/knowledge/findings/socialpolicy/580.asp>

Stronger Links: A guide to good practice for children's family based short-term care services

Vicky Jones, Christine Lenehan and Carol Robinson. The Policy Press. 2000. ISBN: 1861341652

<http://tinyurl.com/nonya>

Together from the Start - Practical guidance for professionals working with disabled children (0-3) and their families. Department of Health and Department for Education and Skills. 2003.

<http://tinyurl.com/optdm>

Useful Websites

The Social Policy Research Unit at the University of York is an independent research unit within the Department of Social Policy and Social Work. The Unit has an international reputation for excellence in research in key areas of social policy, including health and social care, and social security and employment.

<http://www.york.ac.uk/inst/spru/index.htm>

The Norah Fry Research Centre is one of the leading centres in the UK for research into services for people with learning difficulties.

<http://www.bris.ac.uk/Depts/NorahFry>

The Joseph Rowntree Foundation is one of the largest social policy development and research charities in the UK.

<http://www.jrf.org.uk>

Early Support is a national (England) initiative funded by the Department for Education and Skills (DfES) to identify

and develop good service provision for all disabled children aged five and under and their families.

<http://www.earlysupport.org.uk>

Contact a Family has information on over 1,000 rare syndromes and rare disorders.

<http://www.cafamily.org.uk/dirworks.html>

The Disabled Living Foundation provides information for people who use equipment to live a more independent life.

<http://www.dlf.org.uk>

Department for Education and Skills has a Special Educational Needs (SEN) section within its website providing a wide range of advice and materials for teachers, parents and others interested in or working with children with special educational needs.

<http://www.teachernet.gov.uk/wholeschool/sen>

In September 2004, the Department of Health published the **National Service Framework (NSF)** for Children, Young People and Maternity Services. This is the Government's 10 year plan to improve

health and social care for all children in England.

The Children's NSF includes a specific standard around the needs of disabled children, young people and their families; it demands that they receive joined-up services and accurate information.

<http://tinyurl.co.uk/4iag>

The National Service Framework for Children, Young People and Maternity Services in Wales (The children's NSF in Wales) was launched in September 2005. It aims to improve the quality and equity of services for children and young people by setting national standards. It has been developed as a partnership between health and social care with links to education, housing, leisure, the voluntary sector and other stakeholders. There are 21 standards and 203 key actions, which are based on the 42 articles of the UN convention on the Rights of the Child and the Welsh Assembly government's seven core aims for children and young people.

<http://www.wales.nhs.uk/nsf>

The scope of the framework includes all children and young people from birth to 18th birthday but, special consideration will

be given for transition management into adult services beyond the 18th birthday for those requiring support services.

Useful Addresses

If students are interested in writing to these organisations, please send a large stamped addressed envelope with the enquiry.

Afasic

2nd Floor, 50-52 Great Sutton Street, London EC1V 0DJ

<http://www.afasic.org.uk>

Speech Impairment - see also;

<http://www.talkingpoint.org.uk>

Down Syndrome Association

Langdon Down Centre, 2a Langdon Park, Teddington TW11 9PS

<http://www.downs-syndrome.org.uk>

Enable

6th Floor, Buchanan Street, Glasgow G1 3HL

<http://www.enable.org.uk>

Mencap

Mencap, 23 Golden Lane, London EC1Y 0RT

<http://www.mencap.org.uk>



National Autistic Society, 393 City Road, London EC1V 1NG
<http://www.nas.org.uk>

National Deaf Children's Society
15 Dufferin Street, London EC1Y 8UR
<http://www.ndcs.org.uk>

RNIB
105 Judd Street, London WC1H 9NE
<http://www.rnib.org.uk>

Capability Scotland, 11 Ellersly Road, Edinburgh EH12 6HY
<http://www.capability-scotland.org.uk>

Scope
6-10 Market Road, London N7 9PW
<http://www.scope.org.uk>
Cerebral Palsy

Action for Sick Children,
Overmoor, 36 Jacksons Edge Road,
Disley, Stockport, SK12 2JL
<http://www.actionforsickchildren.org>

Carers UK
20-25 Glasshouse Yard, London EC1A 4JT
<http://www.carersonline.org.uk>

Shared Care Scotland
Unit 7, Dunfermline Business Centre,
Isatt Avenue, Dunfermline KY11 3BZ
<http://www.sharedcarescotland.com>

Promotes and supports the development of flexible short break services for people with disabilities in Scotland.

Shared Care Network
Units 63-66, Easton Business Centre,
Felix Road, Bristol BS5 0HE
<http://www.sharedcarenetwork.org.uk>

Promoting family-based short break schemes for disabled children in England, Wales and Northern Ireland.

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Web: <http://tinyurl.com/fmgj> or **Hard-working Families, Caring for two or more disabled children**. Gabrielle Preston 2005
Web: <http://www.disabilityalliance.org/hard.pdf>
- [6] **Paying to Care: The cost of childhood disability**. Barbara Dobson & Sue Middleton, York Publishing Services 1998 ISBN 1 899987 75 4
- [7] **Still Missing out - Ending Child Poverty and Social Exclusion: Messages to Government from Families with Disabled Children**. Neera Sharma. Barnardos. 2002. ISBN 0 902046 87 X
Web: <http://tinyurl.com/fmgr>
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- [10] **Child Poverty review**: July 2004 H M Treasury.
- [11] **Services for disabled children: A review of services for disabled children and their families**. Audit Commission 2003
Web: <http://tinyurl.com/9gbos>
- [12] **Housing Matters: National evidence relating to disabled children and their housing**. Brynary Beresford and Christine Oldman. Policy Press. 2002. ISBN 1 86134 483 X Web: <http://tinyurl.com/fmgt>
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Web: <http://tinyurl.com/fmgu>
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Web: <http://tinyurl.com/fmgx>
- [15] **Still Waiting report?** Shared Care Network 2006
- [16] **Short breaks: Providing better access and more choice for black disabled children and their parents**. Ronny Flynn. The Policy Press. 2002. ISBN 1 86134 428 7
- [17] **Hello! are you listening**. Pippa Murray. York Publishing Services. 2002. ISBN 1 84263 074 1.
Web: <http://tinyurl.com/fmh2>
- [18] **What Works in inclusive education**. Judy Sebba and Darshan Sachdev. Barnardos. 1997. ISBN 0 902046 43 8 Web: <http://tinyurl.com/fmh4>
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Web: <http://tinyurl.com/atq2>
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Web: <http://www.cafamily.org.uk/Psgroups.pdf>
- [21] **The Children Act: Guidance and Regulations: Children with Disabilities**. DoH. 1991. ISBN 0113214529 Web: <http://tinyurl.com/22yx8>

0808 808 3555

Freephone helpline -

Open Mon - Fri 10am - 4pm and Monday 5.30pm - 7.30pm

www.cafamily.org.uk

WWW.makingcontact.org

This factsheet is one of a series produced for parents and groups concerned with the care of disabled children. A selected list can be seen to the right. A full list of Contact a Family publications is available



A Genetic Condition in the Family

A brief introduction to genetics.



Aids, Equipment and Adaptations

Information on where to obtain special equipment.



Living without a Diagnosis

Answers some of the common questions parents have.



Holidays, play and leisure

Provides for people special planning a holiday.



Relationships and caring for a disabled child

Comments from parents.



Working and caring for a disabled child

For parents planning to return to work or who are in employment.



Transition

Identifies the main areas that parents and young people need to think about.

ACENational
action for carers and employment
led by **CARERS** UK

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20 | About families with disabled children | www.cafamily.org.uk

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