

Date of Briefing – August 2005

Being a father to a child with disabilities: issues and what helps

Key messages

- Fathers of disabled children are fathers first, and fathers of a disabled child second. Many of the issues faced by fathers of disabled children are the same as fathers of non-disabled children
- Fathers and mothers of disabled children have many of the same needs and concerns, but there can also be real differences in how they respond to their child's condition, what they do to cope, and what they find helpful
- Fathers can be greatly affected emotionally by a child's disability impairment or illness
- Fathers want information about their child's condition and development, what can be done to help, and what services are available to help their child and the family as a whole
- Fathers tend to rely heavily on their partners for emotional support
- Fathers want someone to talk to from outside the family about their worries and concerns, but are not very good at seeking for this type of help or support. They also prefer support groups made-up of men only because they feel more able to be open in such an environment
- The needs of fathers can be missed by services, which tend to focus on support for the child and mother
- Going to work is a common coping strategy of fathers and important for identity and self-esteem. Fathers want flexibility from employers and services so that they can respond to the needs of their children, attend appointments and be involved in the decisions and care relating to their child

Introduction

This section introduces and defines the scope of the briefing and the topic.

A SCARE briefing provides up-to-date information on a particular topic. It is a concise document summarising the knowledge base in a particular area and is intended as a 'launch pad' or signpost to more in-depth investigation or enquiry. It is not a definitive statement of all evidence on a particular issue. The briefing is divided into the different types of knowledge relevant to health and social care research and practice, as defined by the Social Care Institute for Excellence (SCIE) ⁽¹⁾. It is intended to help health and social care practitioners and policy-makers in their decision-making and practice.

The topic of this briefing is the fathers of children with disabilities, impairments or chronic illness. The children's disabilities include physical or sensory impairments, learning disability, and chronic conditions such as asthma, arthritis, diabetes and congenital heart disease. This briefing focuses on fathers' experiences of their child's disability, impairment or chronic illness, and their resulting needs. Fathers of disabled children experience many of the same needs and concerns as mothers, but they do also have particular issues and needs. Fathers of disabled children are fathers first, and fathers of a disabled child second. Consequently, many of the issues faced by fathers of disabled children are the same as fathers of non-disabled children. Being a parent is an important and positive experience for many fathers, whether their child is disabled or not, and the value men place on being a father to their children is being recognised more and more ⁽²⁾. However, some parenting issues may be more acute or exacerbated by having a child with a disability. For example, mothers and fathers of young children with a disability do experience more depression, as well as more parenting and child-related stress than parents of non-disabled children, and can also feel that their parental situation is more uncontrollable ⁽³⁻⁷⁾. This has been found to be the case even when taking into account socio-economic factors ⁽⁶⁾. However, it must be noted that families vary greatly in how they respond to and cope with having a child with a disability, and how they respond is not determined by the severity of the disability but more often by other factors, such as the child's behaviour generally and the parents' access to social, material and emotional resources ^(5,8,9). The aim of this briefing therefore is to examine the findings of the research literature into the concerns and experiences of fathers of disabled children both generally and specifically. There is no policy or government literature on this topic dealing with fathers alone, so some of the sections below cover services and entitlements for parents of disabled children generally.

Why this issue is important

There is currently very little guidance literature or research concerning fathers of children with disabilities or chronic illness. The literature on families of disabled or chronically ill children tends to focus on the child and mother, and the problems they experience ^(9,10). As in families of non-disabled children, the mothers tend to be the children's primary carer ^(10,11). Services also focus principally on the mother and child ⁽¹⁰⁾. Fathers may therefore be seen as secondary carers only, or may be ignored by health and social services completely ⁽¹⁰⁾. However, it has also been shown that being a parent to a child with a disability or impairment can be as emotionally engaging, as well as distressing, for fathers as for mothers ^(10,12).

The research shows that fathers and mothers share many of the same experiences and responses to being a parent of a disabled child ^(13,14). It is also the case, however, that their experiences, responses, and what they find helpful can differ. For example, fathers have been found to interact differently from mothers with their disabled children ⁽¹⁵⁾. There can also be differences in how fathers and mothers perceive their child's disability or illness and the impact of the child's condition on the parents' self esteem ⁽¹⁶⁾. A study from the US found that mothers and fathers also experience stress from parenting a disabled child differently ⁽⁴⁾. Fathers' stress may be directly related less to their child's behaviour than the stress felt by mothers' ⁽¹⁷⁾. Fathers can also experience less stress, anxiety and depression than mothers, probably because mothers take on the majority of the child care and everyday related tasks ^(3,7,18). Fathers also tend to be less involved and have more limited interaction with their disabled than their non-disabled children, partly because they tend to be more involved in physical activities ^(11,19,20). Unlike mothers, fathers tend to seek support almost entirely from their partner or spouse rather than friends or family ^(5,10,11,13,14,16,19,21-23). Fathers themselves are also heterogeneous as a group: they can have very different experiences of fatherhood, their child's disability, their own needs and what they find helpful ^(10,13,21). Mothers and fathers therefore have both shared and individual needs. These differences need to be taken into account when devising or providing support for families with disabled or chronically ill children. However, this briefing focuses on fathers because as a group they have been considered less in the research and guidance literature.

What do the different sources of knowledge show?

Organisational Knowledge

This section lists and briefly summarises documents that describe the standards that govern the conduct of statutory services, organisations and individuals in relation to the parents of disabled or chronically ill children.

Children Act (2004)

<http://www.opsi.gov.uk/acts/acts2004/20040031.htm>

This Act provides amendments to the Children Act 1989 (see below). The Act states that local authorities have a responsibility for the well-being of children in their area, and in doing so need to acknowledge the importance of parents and other persons caring for children. Part 5 also states that financial assistance may be given for the promotion of the welfare of both children and their parents.

Department of Health (2002). Together from the start. Practical guidance for professionals working with disabled children (birth to third birthday) and their families.

http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4007526&chk=UeTKtE

This guidance has been produced primarily for use by professionals involved with the planning and delivery of services to disabled children. It is designed to improve service provision to very young disabled children and their families.

Employment Act (2002)

<http://www.legislation.hms.gov.uk/acts/acts2002/20020022.htm>

This Act gives working parents of disabled children under 18 the right to request flexible working arrangements. Also, these parents have the right to take (unpaid) time off for dependents in cases of emergency. Working Families makes available a [fact-sheet](#) on flexible working

http://www.workingfamilies.org.uk/asp/family_zone/f_flex_work.asp

Department of Health (2001). Carers and People with Parental Responsibility for Disabled Children. Practice Guidance.

www.carers.gov.uk/pdfs/practiceguidecarersparents.pdf

Part IV of this document gives practice guidance on the provisions of the Carers and Disabled Children Act 2000 as they affect people with a parental responsibility for a disabled child, including access to direct payments and how best to use such funds.

Health and Social Care Act 2001

<http://www.legislation.hms.gov.uk/acts/acts2001/20010015.htm>

This Act enables parents to access direct payments via the Children's Act 1989 to prevent their child becoming or being categorised as "in need".

Department of Health (2001). Valuing People. A New Strategy for Learning Disability for the 21st Century. London, HMSO.

<http://www.archive.official-documents.co.uk/document/cm50/5086/5086.htm>

This White paper forwards proposals for improved service delivery to children with learning disabilities and their parents.

Special Educational Needs Code of Practice (2001). Education Act 1996

<http://www.teachernet.gov.uk/docbank/index.cfm?id=3724>

According to this Code of Practice, plans for a child's education should be worked out in partnership with parents, the child and any relevant agencies.

Department of Health (2000). Framework for the Assessment of Children in Need and their Families. Guidance.

http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4003256&chk=Fss1ka

This guidance draws on research, consultation and best practice to develop a framework for providing services to children and their families, including disabled children.

Carers and Disabled Children Act 2000

<http://www.hmso.gov.uk/acts/acts2000/20000016.htm>

This Act examines the needs and rights of parents or carers who look after those who are in need of additional care, assistance or support because of long-term illness or problems associated with disability. It sets out rights to assessment and the statutory requirements demanded of local authorities. This includes the provision of vouchers and direct payments for parents and carers of disabled children.

Community Care (Direct Payments) Act 1996

<http://www.hmso.gov.uk/acts/acts1996/1996030.htm>

This Act requires local authorities to provide payments in lieu of services directly to those to have been assessed as being in need. It has been argued that this may include services to support parenting ⁽²⁴⁾. Although parenting support is not explicitly assessed as a need in most legislation, the parent may qualify for payments for respite care and other help which can support them in performing their parenting role.

Carers (Recognition and Services) Act 1995

http://www.hmso.gov.uk/acts/acts1995/UKpga_19950012_en_1.htm

This Act deals with the rights of parents and carers who look after elderly, sick or disabled people or children, to receive support from statutory authorities.

Children Act 1989

http://www.legislation.hmsso.gov.uk/acts/acts1989/Ukpga_19890041_en_1.htm

The immediate family is entitled to support if a child is considered to be "in need". Parental needs are considered in a family needs assessment.

Policy Community Knowledge

This section summarises documents describing proposed structural models and guidance for the delivery of policy and improved practice. These documents are published by public policy research bodies, lobby groups, think tanks and related organisations.

Parent Participation: Guide for parents. Improving services for disabled children

http://www.ncb.org.uk/cdc/res_detail.asp?id=676

Parent Participation: Guide for professionals. Improving services for disabled children

http://www.ncb.org.uk/cdc/res_detail.asp?id=671

These guides draw on work carried out by Contact a Family and the Council for Disabled Children with parents and professionals in workshops and a variety of forums. They cover the key principles involved in successful participation.

Council for Disabled Children, Contact a Family. Parent Participation

http://www.ncb.org.uk/projects/project_detail.asp?ProjectNo=285

The aim of this project was to improve services for disabled children by increasing parent participation in the design and delivery of services.

Practitioner Knowledge

This section describes studies carried out by health and social care practitioners, documents relating their experiences regarding the topic, and resources produced by local practitioner bodies to support their work.

Parental Mental Health and Child Welfare Network. Social Care Institute of Excellence (SCIE)

<http://www.scie.org.uk/mhnetwork/index.asp>

This is a network for social care and health workers who work with parents with a mental health problem or their children. It has been set up to promote joint working between adult mental health and children's services. SCIE is also involved in the production of a collaborative guideline on parenting programmes with the National Institute for Clinical Excellence. This guideline is to be published in the future.

London Borough of Waltham Forest Social Services. Parents of Disabled Children.

<http://www.lbwf.gov.uk/index/care/caringforcarers/parentsdischild.htm>

This resource is an example of the local services made available to parents with a disabled child.

Research Knowledge

This section summarises the best available research literature. The focus is on studies undertaken in the United Kingdom, so that the findings are as relevant as possible to the intended audience of the briefing.

The limitations of the research

A substantial amount of research on fathers and parents with disabled children has been conducted in the UK, the United States, Canada, New Zealand, Australia and elsewhere. Studies either focus on fathers alone^(10,12,19,21,22,25-28) or compare mothers and fathers^(3-6,11,13-16,23). This research has a number of limitations, however. The majority of the studies tend to focus on fathers or fathers and mothers of preschool children^(3-6,10,11,13,15,16,19,22,25,26,28); there is less research on fathers or parents of children of school-age or above^(5,14,16,21-23,29). Also, the sampling for many of the studies is convenient and self-selecting: fathers who accept their child fully and have few or no issues with their child's disability are more likely to agree to participate in such studies than fathers who continue to experience problems of acceptance. There is also very little research on fathers and children from ethnic minorities⁽⁹⁾, and none of the studies considers non-resident fathers. The research also tends to focus on identifying the difficulties, needs and concerns of fathers or mothers generally; there is comparatively little research specifically on what they find helpful or on evaluating services which may be helpful, such as key-workers⁽³⁰⁾.

What is the impact of a child's chronic illness or disability on their father?

It is very common for fathers to talk about their disabled children in very positive terms^(10,19,21,31). However, a child's disability, illness or impairment can still have a substantial impact on the father. Some of the literature has found that fathers and mothers of children with disabilities report high levels of stress^(3,4,8,21). It should not be assumed that all fathers of disabled children experience stress or that such stress is directly attributable to their child's disability^(8,10), but studies comparing parents of disabled and non-disabled children have found that the former had much higher levels of child-related stress and depression^(3-7,32). Uncertainty about how best to meet their child's needs, their child's limitations and how they will develop, their education, and where the family can go for practical and emotional support, are all sources of stress for fathers and mothers of disabled children^(3,11,18,21,23,31). Concerns about their child being accepted

socially have also been found to be a greater cause of stress for fathers than mothers of children with intellectual disability ⁽⁵⁾.

Fathers report feeling a range of emotions following the diagnosis of their child's disability or illness. These include mourning, trauma, guilt, denial, feelings of isolation, and a loss of expectations in relation to both their own role as fathers and family life as a whole ^(10,12,19,21,31). One UK study found that most fathers thought their reaction to their child's disability was the same as their partner's, but about one fifth felt that their response was more "practical and rational" in order to support their partner ⁽¹²⁾. Fathers are also more reluctant to seek emotional support than their partners ⁽¹¹⁾. Men's social networks tend to offer less encouragement and accessible support than women's ^(10,27), with the result that fathers rely much more on their partner alone for emotional support ^(5,16,21).

What are the needs of fathers?

The most common finding of the research is that fathers want information about their child's condition and needs, and the resources or services that are available to help their child and family ^(8,10,12,21,23,26). A lack of information about available services, and benefits, can lead to financial hardship ⁽³³⁾. Financial needs are a recurring theme of the research. Fathers report being concerned about the greater financial demands of having a child with a disability or chronic illness, especially the costs of child care; the loss of income from the mother remaining at home; the need for specialised or private transport and for home adaptations or equipment ^(11,22). They also tend to be overlooked by support services, even when the father makes every effort to be involved with his children and is the primary carer or an equal carer with the mother ^(10,12). A study of the use of family centres by fathers of non-disabled children also found that fathers felt that the centres catered more for the needs of mothers as both parents and women than fathers as parents or men ⁽³⁴⁾. The needs of fathers can become less intense over time, however, as they become better acquainted with their child's condition and needs, and develop their own coping mechanisms and sources of support ^(10,21). The issues which are most important for fathers also change over time. The need for information and support becomes less and concerns about the child and the family's future lives can become more insistent ^(10,22,31).

What is helpful?

Fathers find it helpful to have someone to talk to from outside the circle of their family and friends, this could be a health professional, key-worker or support group. They tend to get their emotional support from their partner, and the importance of this mutually supportive relationship has been reported in many studies ^(10,11,14,16,19,22,23). Support groups are considered to be effective by parents of disabled children ⁽²³⁾, and some fathers prefer support groups made up of men only because they feel more able to talk openly in such environments than in mixed groups ^(10,25,35). Some fathers see such groups as meeting a need which may otherwise be unmet by services and other social networks ⁽²⁵⁾. A study examining the role of family centres also found that some fathers felt more able

to talk to male than female support workers, but that very few were available ⁽³⁴⁾. However, it has also been found that when it comes to being involved with their children's early education, fathers of both disabled and non-disabled children prefer to play a role in activities that involve the whole family rather than those which focus on themselves alone ⁽³⁶⁾.

Fathers report that being able to work is helpful, both in terms of providing money to satisfy any additional financial demands from having a disabled child, but also because work was a source of satisfaction and esteem. Surveys have found that parents who work, especially if they have a flexible employer, feel more satisfied and able to cope ^(10,16,19,22,33). However, some fathers acknowledge that working also means that they are less involved with their children ⁽¹⁰⁾, although the demands of work can also mean that they cannot always be there when they want ⁽²¹⁾. A father in one New Zealand study said that having good respite care, in which parents have complete trust, is also important for fathers ⁽²¹⁾.

Fathers find it helpful to have someone to give them practical advice on their child's welfare, education and health, and information generally ^(8,10,21,37). Families want a single point of contact for services and information. Key-workers have been identified as very helpful by both fathers and mothers. These support workers provide important emotional support and help them to identify relevant services ^(9,30,37). Parents also want information to be easy to read, up to date, accurate, and to be available in a variety of formats, such as written, online, and through face to face contact with professionals or key-workers ⁽³⁷⁾. A study from the US found that fathers of children with chronic illness preferred information to be given in films or tapes rather than in written form ⁽²⁶⁾. The provision of key-workers is also a recommendation of the Valuing People strategy document from the Department of Health ⁽³⁸⁾. However, one survey found that less than one third of families with a disabled child had a key-worker ⁽³⁰⁾. Parents generally also report that they find respite services very helpful ^(8,9). Finally, an Australian parent training programme for fathers and mothers of school-aged children with Asperger syndrome found that fathers did not significantly benefit from parent training, unlike mothers ⁽²⁹⁾. However, US studies evaluating the effectiveness of a parent training program specifically for fathers of children with autistic spectrum disorders and developmental disabilities found that the programmes helped the fathers to communicate and interact with their children better, and so derive greater satisfaction from their parenting ^(28,39,40). This can be important because one of the studies also reported how fathers said that they felt frustrated about not knowing how to play or communicate with their autistic child ⁽³⁹⁾. Training programmes may therefore need to be devised specifically for fathers.

Implications for practice

The experiences, needs and concerns of fathers have been shown to be different from mothers and therefore are best served in specific ways. The research makes the following recommendations based on its findings. The reluctance of fathers to seek help means that professionals should take the initiative in

providing the relevant information and details to fathers and mothers about their child's therapy and medication, what they should expect in terms of their child's progress and development, and what resources are available to help them as a family, and themselves as fathers ^(3,4,9,11,21,23,33,35,37). Fathers also need to be encouraged to ask questions, voice their concerns, and be involved as much as possible in the decision-making and care involving their child ^(9,16,22,26). Information has been found to be critical in enabling fathers and mothers to cope better with their situation. There is also a definite role for support groups as a means of emotional support for fathers ^(12,25,35). Both employers and services should offer flexibility for fathers so that they can be there for their child and attend appointments ^(2,26,33). The best long-term support reinforces parents' coping strategies and resources, such as financial support, information on services and the child's condition, and social support from family and friends ⁽⁹⁾.

User & Carer Knowledge

This section summarises the issues raised by fathers in relation to services, both as described by the literature and as defined through local consultation.

Fathers report that support services are provided to the child, mother or family as a whole, but there is no specific help for fathers ⁽¹⁰⁾. One study found that fathers wanted more than one meeting with health professionals because their information needs were constantly changing, and because their ability to ask questions could be compromised at the time of diagnosis by stress or shock ⁽¹²⁾. Fathers also want information about what help is available and report experiencing problems accessing services ^(8,21). They are much less likely to seek support than mothers ^(10,12,13,25), and the lack of services to support the specific and complex needs of fathers mean that they are often left to deal with these needs themselves ⁽¹¹⁾. This is also because they feel an expectation to be strong and to be supportive of their partner ^(10-13,19,25,31). Support with housing and transport is another need identified by both fathers and mothers of disabled children generally ^(8,9). Fathers have also expressed a preference for services which are flexible and make provision during times when working fathers are available ^(2,9,33).

Useful Links

This section lists sources of information relevant to professionals who work within this field, and may also be of value to service users.

Children and Families. Department for Education and Skills
<http://www.dfes.gov.uk/childrenandfamilies/>

This document provides links to a range of government and non-government bodies and organisations. This was formerly Quality Protects.

Choices. For Families of Children with Arthritis

<http://www.kidswitharthritis.org/>

This website makes available a fact-sheet (<http://www.kidswitharthritis.org/factsheets/factsheet13.html>) for fathers of children with arthritis written by fathers of children with this chronic condition.

Contact a Family

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

Contact a Family is a charity providing support and advice to parents of children diagnosed with disability, rare syndromes or chronic illnesses. The website provides a section of the site for fathers (<http://www.cafamily.org.uk/dads.html>), as well as making available fact-sheets for fathers (<http://www.cafamily.org.uk/fathers.html>) and professionals (<http://www.cafamily.org.uk/students.html>), and about available financial benefits (<http://www.cafamily.org.uk/benefits.html>). The website also has a section listing projects and organisations to help parents of disabled children with regard to education, counselling, services, leisure and finance (<http://www.cafamily.org.uk/whenyourchild.html#Anchor-Educatio-46089>)

Council for Disabled Children

<http://www.ncb.org.uk/cdc/>

This organisation is a national forum for the discussion, development and dissemination of policy and practice issues for disabled children and young people and those with special educational needs.

Disability Information Service. Queen Elizabeth's Foundation.

<http://www.diss.org.uk/index.html>

This website offers a database of the main UK organisations, support groups and other help-lines working in the disability field, and contact information for local disability information services.

Fathers Direct

<http://www.fathersdirect.com/>

Fathers Direct is a registered charity and an information centre on fatherhood. It was founded in 1999 by professionals with expertise in social work, family policy, business development and communications.

Foundation for People with Learning Disabilities

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

This Foundation seeks to promote the rights, quality of life and opportunities of people with learning disabilities and their families. It is currently involved in a project called "2Recognising Fathers" which aims to develop a better understanding of the issues faced by fathers of children with a learning disability.

Learning Disabilities. Department of Health

<http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LearningDisabilities/fs/en>

The website provides information about Government policy, white papers, working groups, and relevant links, for adults and children with learning disabilities.

National Family and Parenting Institute (NFPI)

<http://www.nfpi.org/>

The National Family and Parenting Institute (NFPI) is an independent charity working to support parents in bringing up their children and to promote the well-being of families.

NCB Council for Disabled Children

<http://www.ncb.org.uk/cdc/intro.asp>

The Council for Disabled Children provides a national forum for the discussion and development of a wide range of policy and practice issues relating to service provision and support for disabled children and young people and those with special educational needs.

Parentline Plus

<http://www.parentlineplus.org.uk/templates/home/index.cfm>

Parentline Plus is a national charity that works for and with parents. It works to offer help and support through a range of free and flexible services.

Royal College of Psychiatrists (2004). Mental Health and Growing Up, Third Edition. Good parenting

<http://www.rcpsych.ac.uk/info/mhgu/newmhgu2.htm>

The Royal College of Psychiatrists produces fact-sheets for parents, teachers and young people entitled Mental Health and Growing Up. The aims of these fact-sheets are to provide practical, up-to-date information about mental health problems (emotional, behavioural and psychiatric disorders) that can affect children and young people.

Sure Start

<http://www.surestart.gov.uk/>

Sure Start is a Government programme which aims to achieve better outcomes for children, parents and communities by supporting parents as parents, and by improving and increasing access to child care.

Teachernet. SEN Strategy

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

This is the government's Strategy for enabling children with special educational needs to realise their potential. It is a programme of sustained action and review over a number of years to support early years settings, schools and local

authorities in improving provision for children with Special Educational Needs. This includes making available a Guide for parents and carers of children with SEN

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

Working Families

http://www.workingfamilies.org.uk/asp/family_zone/f_welcome.asp

This resource offers information about workers rights and eligibility for benefits, as well as practical support for re-entering work for families. There are sections for both fathers and disabled children.

Related SCARE briefings

Transition of Young People with Physical Disabilities or Chronic Illnesses from Children's to Adults' Services

Title link: <http://www.scie.org.uk/publications/briefings/briefing04/index.asp>

Short Breaks (Respite Care) for Children with Learning Disabilities

Title link: <http://www.scie.org.uk/publications/briefings/briefing05/index.asp>

ADHD: Background, Assessment and Diagnosis

Title link: <http://www.scie.org.uk/publications/briefings/briefing07/index.asp>

ADHD: How it is treated

Title link: <http://www.scie.org.uk/publications/briefings/briefing08/index.asp>

Acknowledgements

Thank you to the experts and service users for their contributions to this briefing.

References

1 **Pawson R., Boaz A., Grayson L., Long A., Barnes C.** (2003). Types and Quality of Knowledge in Social Care. Knowledge Review 3. Social Care Institute for Excellence (SCIE). **Title link:**

<http://www.scie.org.uk/publications/knowledge.asp> [Accessed 18 October 2005]

This document analyses and defines the different types of knowledge and information which may inform social care research and practice

2 **Carpenter B.** (2002). Inside the portrait of a family: the importance of fatherhood. *Early Child Development and Care*, 172 (2), 195-202.

This article reviews and extends the debate on the redefinition of fatherhood. Full text available <http://www.fathersdirect.com/index.php?id=15&cID=259>

3 **Pelchat D., Ricard N., Bouchard J.M., Perreault M., Saucier J.F., Berthiaume M. et al.** (1999). Adaptation of parents in relation to their 6-month-old infant's type of disability. *Child: Care, Health and Development*, 25 (5), 377-397.

This Canadian study measured the different levels of stress among parents of infants with different disabilities.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10494463&dopt=Abstract

4 **Esdaille S.A., Greenwood K.A.** (2003). A comparison of mothers' and fathers' experience of parenting stress and attributions for parent-child interaction outcomes. *Occupational Therapy International*, 10 (2), 115-126.

This US study explores differences in parenting stress between mothers and fathers of disabled children.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12897895&dopt=Abstract

5 **Saloviita T, Italinna M, Leinonen E** (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: A Double ABCX model. *Journal of Intellectual Disability Research*, 47 (4-5), 300-312.

This Finnish study examines the factors which contribute to stress in parents of children with an intellectual disability.

Abstract available:

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12787162&dopt=Abstract

6 Roach M.A., Orsmond G.I., Barratt M.S. (1999). Mothers and fathers of children with Down syndrome: Parental stress and involvement in childcare. *American Journal on Mental Retardation*, 104 (5), 422-436.

This US study compares parental stress in socio-economically matched samples of mothers and fathers of children with Down syndrome and parents of typically developing children.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10541413&dopt=Citation

7 Veisson M. (1999). Depression symptoms and emotional states in parents of disabled and non-disabled children. *Social Behavior and Personality*, 27 (1), 87-97.

This article is a survey from Estonia comparing the depressive symptoms and emotional states of parents of disabled children and non-disabled children.

Full text available

http://www.findarticles.com/p/articles/mi_qa3852/is_199901/ai_n8851290

8 Sloper P. (1999). Models of service support for parents of disabled children. What do we know? What do we need to know? *Child: Care, Health and Development*, 25 (2), 85-99.

This paper reviews the findings about parental stress and coping strategies, and identifies a number of important characteristics of effective service models.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10188064&dopt=Abstract

9 Beresford B., Sloper P., Baldwin S., Newman T. (1996). What Works in Services for Families with a Disabled Child. Barnardos. **Title link:** <http://www.barnardos.org.uk/resources/researchpublications/documents/wwdisab.pdf> [Accessed 18 October 2005]

This report discusses effective practice for families with disabled children up to the age of 16.

10 West S. (2000). Just a shadow: a review of support for fathers of children with disabilities. Birmingham, Handsel Trust.

This book reports the findings of interviews with four fathers of children with disabilities.

11 Pelchat D., Lefebvre H., Perreault M. (2003). Differences and similarities between mothers' and fathers' experiences of parenting a child with a disability.

Journal of Child Health Care, 7 (4), 231-247.

This Canadian study uses focus groups to identify the differences and similarities in the experiences of parents of children with a disability.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=14636429&dopt=Abstract

12 **Rendall A.** (1997). Fatherhood and learning disabilities: a personal account of reaction and resolution. *Journal of Learning Disabilities*, 1 (2), 77-83.

This article describes the findings of a survey of fathers of children with disabilities, as well as the author's personal experience.

13 **Sullivan A.** (2002). Gender differences in coping strategies of parents of children with Down syndrome. *Down Syndrome: Research & Practice*, 8 (2), 67-73.

This UK examines the reactions of fathers compared to mothers following the birth of a child with Down syndrome.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12407971&dopt=Abstract

14 **Knafli K., Zoeller L.** (2000). Childhood chronic illness: a comparison of mothers' and fathers' experiences. *Journal of Family Nursing*, 6 (3), 287-302.

This US study explores how mothers and fathers of a child with a chronic illness view their experience and its impact on family life.

15 **Fidalgo Z., Pimentel J.S.** (2004). Mother, child and father-child interactions with Down syndrome (DS) children: A comparative study. *Journal of Intellectual Disability Research*, 48 (4-5), 326.

This Portuguese study examines differences between fathers and mothers in how they interact with their disabled children.

16 **Katz S.** (2002). Gender differences in adapting to a child's chronic illness: a causal model. *Journal of Pediatric Nursing*, 17 (4), 257-269.

This Israeli study examines differences between mothers and fathers' response to their child's chronic illness.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12219325&dopt=Abstract

17 **Hastings R.P.** (2003). Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children of autism. *Journal of Intellectual Disability Research*, 47 (4-5), 231-237.

This UK study examines the relationship between maternal and paternal psychological well-being and being the parent of a disabled child.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12787155&dopt=Abstract

18 **Pelchat D., Bisson J., Ricard N., Perreault M., Bouchard J.-M.** (1999). The longitudinal effects of an early family intervention program on the adaptation of families of children with a disability. *International Journal of Nursing Studies*, 36 (6), 465-477

19 **Peck B., Lillibridge J.** (2003). Rural fathers' experiences of loss in day-to-day life with chronically ill children. *Australian Journal of Advanced Nursing*, 21 (1), 21-27.

This is an Australian study of the experiences of rural fathers in relation to their disabled children.

20 **Seiffge-Krenke I.** (2002). "Come on, say something, Dad!": communication and coping in fathers of diabetic adolescents. *Journal of Pediatric Psychology*, 27 (5), 439-450.

This German study compares the coping and communication behaviour of fathers in families with either a diabetic or a non-diabetic child.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12058008&dopt=Abstract

21 **Donald Beasley Institute.** (1997). *Perilous Passage: New Zealand Fathers Talk about their Children with Disabilities*. Dunedin, The Donald Beasley Institute Inc.

This book describes the experiences of fathers of disabled children and offers an insight into their relationships.

22 **Goble L.A.** (2004). The impact of a child's chronic illness on fathers. *Issues in Comprehensive Pediatric Nursing*, 27 (3), 153-162.

This US study examines the experience of fathers of a child with a chronic illness.

Abstract available:

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=15371113

23 **Leyser Y., Heinze T.** (2001). Perspectives of parents of children who are visually impaired: Implications for the field. *RE:view*, 33 (1), 37-48.

This US survey examines what parents of visually impaired children find both difficult and helpful.

Abstract available

<http://static.highbeam.com/r/review/march222001/perspectivesofparentsofchildrenwhoarevisuallyimpai/>

24 **Olsen R., Wates M.** (2003). Disabled Parents. Examining Research Assumptions. *Research in Practice*. **Title link:** <http://www.rip.org.uk/publications/researchreviews.asp> [Accessed 18 October 2005]

The aim of this review is to bring together the research literature on disabled parents and to place it within the context of policy and practice.

25 **West A.** (1998). The piloting of a group for the fathers of children with Down syndrome. *Child: Care Health and Development*, 24 (4), 289-294.

This paper describes the piloting of a small group for the fathers of children with Down Syndrome.

Abstract available:

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9693857&dopt=Abstract

26 **Hadadian A., Merbler J.** (1995). Fathers of young children with disabilities: how do they want to be involved? *Child and Youth Care Forum*, 24 (5), 327-338.

This US study looks at father's involvement with their disabled children, as well as their training and resource needs.

27 **Quinn P.** (1999). Supporting and encouraging father involvement in families of children who have a disability. *Child and Adolescent Social Work Journal*, 16 (6), 439-454.

This US study looks at interventions to improve fathers' involvement with their disabled children.

28 **Russell D., Matson J.** (1998). Fathers as intervention agents for their children with developmental disabilities. *Child & Family Behavior Therapy*, 20 (3), 29-49.

This US study examines the effectiveness of parent training for three fathers of developmentally disabled children.

29 **Sofronoff K., Farbotko M.** (2002). The effectiveness of parent management training to increase self-efficacy in parents of children with Asperger syndrome. *Autism*, 6 (3), 271-286.

This Australian study looks at an intervention programme to improve parental self-efficacy in the management of problem behaviours associated with Asperger syndrome.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=12212918

30 **Beresford B.** (1995). *Expert Opinions: a Survey of Parents Caring for a Severely Disabled Child*. Bristol, Policy Press.

This is a survey of parents of disabled children. It focuses on available and recommended services.

31 **Meyer D.J.** (1995). *Uncommon Fathers: Reflections on Raising a Child with a Disability*. Bethesda M.D., Woodbine House.

The nineteen chapters of this U.S. book were written by fathers of children with disabilities. They describe their experiences.

32 **Olsson M.B., Hwang C.P.** (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, 45 (6), 535-543.

This Swedish study compares depression in parents of children with autism and intellectual disabilities with parents of non-disabled children.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=11737541

33 **Kagan C., Lewis S., Heaton P.** (1998). *Caring to Work: Accounts of working parents of disabled children*. Joseph Rowntree Foundation. **Title link:**

<http://www.jrf.org.uk/knowledge/findings/socialcare/SCR538.asp>

This is a report on the needs and experiences of 40 families with disabled children, especially in terms of employment and work.

34 **Ghate D., Shaw C., Hazel N.** (2000). *Fathers and Family Centres: Engaging Fathers in Preventive Services*. Joseph Rowntree Foundation. **Title link:**

<http://www.jrf.org.uk/knowledge/findings/socialpolicy/330.asp> [Accessed 18 October 2005]

This study examines what helps and hinders fathers' involvement with family centres

35 **Carpenter B., Addenbrooke M., Attfield E., Conway S.** (2004). "Celebrating Families": an inclusive model of family-centred training. *British Journal of Special Education*, 31 (2), 75-80.

This article reports on a week of training days for all members of families of children with special needs, including fathers, extended family and siblings.

36 **Turbiville V.P., Marquis J.G.** (2001). Father participation in early education programs. *Topics in Early Childhood Special Education*, 21 (4), 223-231.

This US study examines the involvement of 318 fathers of disabled and non-disabled children in early education programmes.

37 **Mitchell W., Sloper P.** (2000). User-friendly information for families with disabled children: A guide to good practice. Joseph Rowntree Foundation. **Title link:** <http://www.jrf.org.uk/knowledge/findings/socialcare/n30.asp> [Accessed 18 October 2005]

This is a report on a project investigating the information and service needs of parents of disabled children.

38 **Department of Health** (2001). Valuing People. A New Strategy for Learning Disability for the 21st Century. Department of Health. **Title link:** <http://www.archive.official-documents.co.uk/document/cm50/5086/5086.htm> [Accessed 18 October 2005]

This White paper forwards proposals for improved service delivery to children with learning disabilities and their parents, as well as adults with learning disabilities.

39 **Elder J.H., Valcante G., Won D., Zylis R.** (2003). Effects of in-home training for culturally diverse fathers of children with autism. *Issues in Mental Health Nursing*, 24 (3), 273-295.

This US study reports on four fathers from different ethnic groups and the effect of a programme to help their parenting.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12623686&dopt=Abstract

40 **Elder J.H., Valcante G., Yarandi H., White D., Elder T.H.** (2005). Evaluating in-home training for fathers of children with autism using single-subject experimentation and group analysis methods. *Nursing Research*, 54 (1), 22-32.

This US study evaluates a training program designed to help fathers interact better with their autistic children.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=15695936&query_hl=1