

Date of Briefing – February 2005

Helping parents with a physical or sensory impairment in their role as parents

Key messages

- Eligibility criteria are applied by social services to the parenting needs of all parents.
- The parenting responsibilities and role of disabled parents needs to be recognised, and policies developed across community care services to support this role.
- Potential barriers to the development and maintenance of specialised and/or multi-agency services for disabled parents include limited funding, a lack of skills among professionals for assessing the needs of disabled parents, and entrenched attitudes about the respective services' responsibilities towards children and adults.
- Much research looks only at the experiences of parents primarily in terms of their physical or sensory impairments, and the barriers they face as a direct result of their impairments, rather than examining the broader social barriers encountered by disabled parents.
- The research reports that parents with physical or sensory impairments can experience great difficulty in performing a range of domestic and child care tasks. However, parents do develop coping strategies, and there are environmental and physical means of supporting these parents in their roles.
- Direct payments are also valued by parents because they can arrange help to suit their own needs, rather than having to accept the less flexible support provided by other services.

Introduction

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

A SCIE 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 parents with physical or sensory impairments and ways of addressing any perceived barriers to their parenting. This briefing does not consider any supposed impact of a parent's disability on their children, but only describes some of the specialist requirements of parents with physical or sensory impairments. For reasons of space and consistency this briefing does not cover parents with learning disabilities, HIV/AIDS, mental health problems or some form of addiction, or pregnancy and childbirth among disabled women. Parents with physical or sensory impairments may also experience one or more of these other conditions, but these issues are not considered separately in this briefing, only where the combination is specifically addressed by the research. Also, the type of support most effective for parents who have learning disabilities or issues with substance misuse is in some ways quite distinct from what parents with physical or sensory impairments find helpful, and is therefore covered by other briefings in this series ^(2,3). Nor does this briefing cover disabled parents with disabled children. The parents covered by this briefing are those with physical disabilities such as arthritis, asthma, cystic fibrosis, cerebral palsy, multiple sclerosis, end stage renal disease, neuromuscular diseases, spinal cord injury, and also those with various degrees of deafness and blindness. The parents covered by this briefing do not constitute a clearly homogenous group, but their parenting has particular common themes, such as a potential need for assistance with looking after children, domestic tasks and transportation ⁽⁴⁾.

It is acknowledged that many parents with physical impairments do not need to look to social services or other professionals for assistance with their parenting ⁽⁵⁻⁷⁾, and that other factors such as family structure, poverty and social exclusion are important and affect any parent's ability to perform their role ⁽⁶⁻⁸⁾. Parents with the same physical or sensory impairment can also have differences in terms of their needs, capabilities and limitations. How individual parents respond to the issues raised by their impairment and these socio-economic variables can differ from person to person also. It is also acknowledged that services in local authorities tend to be organised according to either medical or social categories, rather than the more holistic reality of family life, and that parents with physical or sensory impairments encounter many of the same social and organisational

barriers as parents with other forms of disability. The briefing focuses on what some parents find helpful when faced with disabling barriers.

The aim of this briefing therefore is only to examine the general findings of the research and policy literature into how to overcome the barriers experienced by parents with physical or sensory impairments in their parenting, if such help is required. This focuses on helping them as parents with regard to certain aspects of their disability, as well as alleviating any broader, relevant socio-economic elements. It must be stressed therefore that this briefing is “parent-centred”, but may be read in conjunction with the briefing on young carers, which is “child-centred”⁽⁹⁾. In combination, the two briefings hopefully offer a balanced examination of the topic.

Why this issue is important

This section summarises research findings relating to parents with disabilities, as well as the key characteristics of this group.

Factors demonstrated as having an adverse effect on parenting include low socio-economic status; unemployment; and social isolation or exclusion^(7,10,11). All of these factors make parenting difficult, and parents with physical or sensory impairments can be at greater risk of experiencing one or more of these disadvantages than other parents. There are 2.1 million disabled parents in the United Kingdom⁽¹⁰⁾. A parent’s disability is also a social exclusion issue. In almost two thirds of households where no-one was working and one or both parents were disabled, then the family lived “in poverty”⁽¹²⁾. Disabled people of working age are also “around seven times more likely as non-disabled people to be out of work and claiming benefit”⁽¹³⁾. As a group, parents with physical disabilities or impairments also experience negative attitudes from other people towards their parenting, especially assumptions that they either cannot be a parent or are not able to look after their children properly⁽¹⁴⁻¹⁶⁾. They can therefore feel that they have to work harder than other parents in order to be accepted as competent⁽¹⁴⁾. It has also been demonstrated that if a mother or father cannot fulfil their role as a parent, according both to their own and others socially defined expectations, then this may affect their self-esteem and self-image, and generate feelings of anxiety, frustration and guilt^(5,14,17-19).

Disability benefits do not take account of the potentially higher costs of parenting incurred by parents with physical or sensory impairments compared to other disabled people or non-disabled parents. For example, adaptations and equipment for parents and the safety of their children; the increased reliance on convenience foods; heating and laundry costs; limited access to many of the least expensive social activities; the need to pay for help from support workers, including child care and domestic tasks such as cleaning; and increased

transport costs and inconvenience ^(16,20). Current benefits are inadequate for meeting these additional expenses ⁽²⁰⁾. Disabled parents can therefore experience the double problem of lower incomes and higher living costs, which in turn leads to social exclusion ⁽¹³⁾. Finally, an Inspection of the provisions of social services for disabled parents found that the focus appeared to be “either on the children in the family or on the impact of the adults’ disability on their personal needs . . . and seldom focused on the whole family and how to support and help the parents in the discharge of their parental duties in their social setting” ⁽²⁴⁾.

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 provision of support to disabled parents.

Prime Minister's Strategy Unit (2005). Improving the Life Chances of Disabled People

http://www.strategy.gov.uk/work_areas/disability/index.asp

This report sets out a programme to support "disabled people to help themselves" by participation and inclusion.

Department of Health (2003). Fair Access to Care Services. Practice Guidance

<http://www.dh.gov.uk/assetRoot/04/01/97/34/04019734.pdf>

This guidance provides councils with a framework for setting their eligibility criteria for adult social care. It emphasises that reviews of individual service users' circumstances should be carried out by appropriate council professionals on a regular and routine basis. This guidance document recommends that local authorities acknowledge and support the possible needs of disabled parents in their “parenting roles and responsibilities”. This includes "if adult parents have care needs that affect their parenting abilities and possibly impact on the well-being of their children, then councils should consider their duties under the Children Act 1989 and the . . . Framework for the Assessment of Children in Need and their Families”, and, "Even though children may be well-cared for in a domestic situation, an adult parent's well-being could be undermined, and problems exacerbated, if s/he is not able to fulfil the parenting role s/he aspires to".

Every Child Matters (2003)

<http://www.rcu.gov.uk/articles/news/everychildmatters.pdf>

The Every Child Matters: Change for Children programme is a new approach to the welfare of all children and young people. It is focused around the five Every

Child Matters outcomes, which aim for all children and young people to be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic well-being. However, it is also intended to deliver better information and support to parents and carers who need help, from maternity right through the teenage years.

Health and Social Care Act 2001

<http://www.legislation.hmso.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" ⁽²²⁾.

Department of Health (2001). National Service Framework for Children, Young People and Maternity Services

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

The Children's National Service Framework (NSF), published on 15 September 2004, sets standards for children's health and social services, and the interface of those services with education.

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 document describes a framework for assessing children's and families needs to identify "whether the child being assessed is in need . . . and which services would best meet the needs of this child and their family". The needs of disabled family members must also be considered.

Human Rights Act 1998

<http://www.hmso.gov.uk/acts/acts1998/19980042.htm>

This Act requires that there should be no discrimination in access to services on grounds on disability, the right to marry or have a family, and that cultural and linguistic differences should be taken into account in the provision and delivery of services.

Community Care (Direct Payments) Act 1996

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

This Act enables local authorities to provide payments in lieu of services directly to those who have been assessed as being in need. This may include services to support parenting.

Disability Discrimination Act 1995

<http://www.disability.gov.uk/dda/>

Part 3 of this Act covers the provision of goods, facilities and services. This Act sets down that it is unlawful for a service provider to discriminate against a

disabled person. Local authorities, as well as the voluntary and independent sector, must ensure that any services offered to parents are equally available to parents with disabilities or impairments. The Disability Discrimination Act 2005 (<http://www.legislation.hmso.gov.uk/acts/acts2005/20050013.htm>) also demands that these services and organisations “promote equality of opportunity” for disabled parents.

National Health Service (NHS) and Community Care Act 1990

http://www.legislation.hmso.gov.uk/acts/acts1990/Ukpga_19900019_en_1.htm

This Act aims to enable people with physical or other needs to live in their own homes. The emphasis is on independence. This includes disabled parents. Local authorities are required by this Act to carry out assessments of anyone who appears in need of community care services. If the person being assessed is disabled then according to related legislation cited in the Act, the practical needs of that person, in terms of their “greater safety, comfort or convenience” must be assessed.

Children Act 1989

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

This Act does not assume that children are “in need” simply because a parent has an impairment. It does assume however that children are best cared-for within their own family, and so parents should receive any support they need to perform their parenting role, and therefore protect the welfare of the child.

Policy Community Knowledge

This section summarises documents describing proposed structural models or 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.

Gooding S. (2000) A Jigsaw of Services: Inspection of services to support disabled adults in their parenting role. London, Department of Health

http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsInspectionReports/PublicationsInspectionReportsArticle/fs/en?CONTENT_ID=4005103&chk=hgrdpj

This is a report based on inspections of arrangements for providing support to disabled adults in eight local council areas. The experience and views of service users acted as a significant focus for the inspection. The key messages section includes examples of good practice, as well as practice recommendations. The Inspection recommended that social services better recognise the parenting responsibilities and role of disabled adults, and that policies need to be developed across community care and children’s services to support this role.

However, research has also found that the recommendations of this document are not consistently being put into practice ⁽²³⁾.

Recommended standards for the provision of services to disabled parents to support their parenting role as examined by the Inspection
<http://www.dh.gov.uk/assetRoot/04/03/56/20/04035620.pdf>

Olsen R., Tyers H. (2004). Think Parent: Supporting Disabled Adults as Parents
<http://www.nfpi.org/data/publications/>

This is a new guide for social care professionals. It aims to ensure that support for disabled parents is encouraged and developed across the social services network. The authors examine policy and legislation; assessments of parents; messages from existing research; disabled parents' views on support; and examples of best practice from four key local authorities.

One review of the literature advances twenty-eight questions for local authorities which they "may find useful as a basis for enquiring into existing practices" ⁽²²⁾. These include issues of co-operation between existing services, parenting as a specific need, parents' access to relevant information and disabled parents' input into the development of services. Greater co-operation between adults' and children's services is a key recommendation of much of the research and policy literature ^(20,22,24-26), as is a specific assessment of parenting needs ^(20,26) and the involvement of disabled parents in the development of policy ^(20,22,23). It has also been pointed out that the need for improved co-ordination of statutory services in order to support families is made more difficult by the current trend to separate adult and children's services ⁽⁷⁾.

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.

Goodinge S. (2000). A Jigsaw of Services. Inspection of services to support disabled adults perform their parenting role: Key messages for practitioners and first-line managers. London, Department of Health.

http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsInspectionReports/PublicationsInspectionReportsArticle/fs/en?CONTENT_ID=4007913&chk=pEzbyV

The key messages include examples of good practice and practice recommendations.

Olsen R., Tyers H. (2004). Think Parent: Supporting Disabled Adults as Parents
<http://www.nfpi.org/data/publications/>

This guide contains examples of best practice from four key local authorities.

A set of practice recommendations have also been made for breastfeeding by mothers with arthritis, based on research conducted with mothers and health professionals ⁽²⁷⁾. These include the mother's posture and positioning, the need to take into account any medication that is being taken for arthritis, and also the recommendation that health visitors, GPs, physiotherapists and occupational therapists work closely together to support the mother.

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

There is research on parenting by parents with sensory impairments ^(15,28-30), chronic illnesses such as arthritis ^(5,17,31-33), asthma ⁽³⁴⁾ and kidney disease ⁽¹⁹⁾, and a range of other conditions producing physical or sensory impairments ^(8,10,14,18,20,23,35-37). However, the literature otherwise tends to cover physical or sensory impairment only in association with learning disability, or more generally in literature on young carers ^(20,23,25,38,39). Some studies are concerned solely with the experiences of mothers ^(5,14,15,17,18,34,35,37). Much of the remainder of the research focuses on both parents, but tends to equate parenting with mothering, or chooses methods which result in mothers taking more of a part in the research than fathers. Also, many of the research studies cited in this briefing are from the US and Canada ^(4,5,8,15,19,30,34-37,40); only about half of the papers identified for this briefing actually report on research from the UK ^(15,17,28,29,31,32). The vast majority of the research focuses only on practical help to relieve the physical difficulties posed by a parent's disability; there is very little literature on how to alleviate the broader social difficulties that may be experienced by parents with physical or sensory impairments, such as poverty, housing, employment, and social networks. This aspect is addressed more in the Organisational, Policy Community and Practitioner Knowledge sections above.

All of the studies reported here offer original insights into the topic. The type of weaknesses which affect the research include a lack of detail on method, data collection and analysis ^(14,31-33,38), and insufficient reported data to support the findings ^(14,15,32,33), and issues concerning recruitment ^(14,15,18,32,33). These limitations need to be taken into account when considering the research findings set out below. It is also important to stress that the research described here looks at the experiences of parents primarily in terms of the specialist requirements generated by their physical or sensory impairments, and the barriers they face as

a direct result of their impairments, rather than examining the broader social barriers encountered by disabled parents.

Which interventions may support parents with disabilities perform their parenting role?

The research has shown that several domestic and child care tasks may present a barrier for parents with physical or sensory impairments ^(5,8,14,15,17,19,28,30-35). Parents with physical or sensory impairments may also experience financial difficulties because they may be unable to work, and may therefore also have little disposable income to spend on activities with their children ⁽¹⁹⁾. The principal challenges experienced by parents with physical or sensory impairments are those created by inaccessible environments and forms of communication.

Physiotherapists and occupational therapists have identified several solutions to enable parents with arthritis to fulfil their parenting role more in accordance with their own expectations. These include techniques to avoid pressure on joints, alternative methods of lifting and handling children, and advice on changes in and to the home, such as adapting furniture ⁽³³⁾. The provision of appropriate, adapted equipment to help parents in their parenting, especially of young children, is a constant theme of the research ^(17,35,36,40). The research has also found, however, that there is a lack of appropriate products to support certain aspects of parenting, for example, pushing a pram or buggy, or carrying a baby when the mother is in a wheelchair ⁽³⁵⁾.

The research has consistently found that modifying the home, to make it more accessible to the parent, makes parenting easier, especially in the performance of domestic household tasks, which mothers consider to be an important part of being a parent ^(17,35,37). However, parents may be prevented from implementing such modifications by financial or practical restrictions ⁽³⁵⁾. In such cases, a possible solution is to provide mothers with some form of home help ^(17,35). The research has also emphasised that parents need to be encouraged to seek support from statutory and voluntary services ^(28,31,33). Medical solutions, such as the provision of effective drug information and management, are important for parents with debilitating physical conditions, such as arthritis and asthma: parents who receive appropriate treatment are more able to perform their parental role than those whose condition is managed less well ^(5,33,34).

This research has important limitations, however. The studies tend to consider only small samples; they do not compare their findings with control groups; and they focus only on the problems or difficulties experienced by disabled parents as a direct result of their physical or sensory impairments, rather than evaluating any proposed or perceived solutions. For example, although transport is a key issue for this group of parents, no clear, tested solutions have been examined by research. This is the same for many of the supportive measures recommended by the research. The literature examines the challenges and issues faced by parents with physical or sensory impairments, and makes recommendations

about how to address them, such as adapted equipment or modifications to the home, but there is little research on effectiveness of the proposed solutions ^(36,40). Few studies report findings about parents who do not experience any problems in their parenting ⁽⁵⁾.

What are the barriers to providing effective parenting support services to parents with physical disabilities?

One of the principal barriers to the provision of support to parents with physical or sensory impairments is the blurring of responsibilities between adults' and children's services ^(20,23,25). Children's services tend to focus exclusively on assessing children's needs and welfare, including child protection issues; adult services tend to focus only on the provision of personal services to disabled adults. The needs of disabled parents therefore often fall between these two services, but "professional agendas can be divergent and sometimes contradictory, and knowledge about the work of other professionals is often limited" ⁽⁴¹⁾.

Generally, a "whole-family" approach is advocated, which seeks to address the needs of the parent and child together rather than separately ^(7,25,38,42-46). The potential barriers to the development and maintenance of specialised and/or multi-agency services for disabled parents have been identified as limited funding, lack of skills among professionals for assessing the parenting needs of disabled people, and entrenched attitudes about the respective services' responsibilities towards children and adults ⁽⁴¹⁾. Multi-agency working needs to be very carefully structured and co-ordinated in order to promote consistency and continuity of information and services between the many professionals involved ⁽⁴⁷⁾. Services should be developed in conjunction with parents and their advocates ^(20,23).

User & Carer Knowledge

This section summarises the issues raised by service users and carers in relation to this topic, both as described by the literature and as defined through local consultation.

Parents with physical disabilities or impairments experience several barriers to their parenting. They have reported how inaccessible environments can place substantial limitations on them as parents, sometimes preventing them from accompanying their children ^(15,28,35,37). Parents with musculoskeletal conditions, such as arthritis, report that the fatigue, pain and the physical limitations imposed by their condition can also adversely affect their ability to meet their own expectations of parenting ^(5,17,31-33). Some mothers with arthritis say they have special difficulty in performing a range of child care tasks for young children, while fathers experience their greatest frustration in being unable to engage in

physical activities with their children, especially when the children become older⁽³¹⁾. Other mothers with rheumatoid arthritis have also said that the more severe their symptoms, then the more distressed they become about their ability to perform their parenting role⁽⁵⁾. Parents with physical disabilities also stress their reliance on help with transport, or the need for specialised transport^(17,35,40). The research has also demonstrated that appropriate equipment and techniques to aid lifting and carrying are valued by parents and improve parents' physical interaction with their children, making it less stressful and less painful, as well as generating greater feelings of independence and making them more confident about their children's safety^(17,36,40,48).

Deaf parents have said that they want practical, technical support to help them in their parenting⁽²⁸⁾. This includes appropriate equipment to alert them to when their babies are crying, and more access to interpreters, such as practitioners of British Sign Language (BSL), to help them participate in their children's school events and engage effectively with teachers on parents' evenings⁽²⁸⁾. Mothers with arthritis, multiple sclerosis and visual impairment have also highlighted the value of aids and adaptations (including adaptations to equipment such as cots and buggies), and practical help, from partners, relatives or home helps, with basic care tasks for very young children, such as lifting, bending or bathing^(17,31). However, it can be difficult to judge the appropriate amount of help or equipment wanted by a disabled parent faced with access, communication or mobility issues: some value all the help they receive from partners and family, others may seek less help, and can find the involvement of others unnecessary and intrusive, preventing them from fulfilling their role as a parent in the way they want^(17,18). Parents have described defining clear boundaries in role and responsibilities, with partners, other family members and support services, to be an effective means of helping them to perform their parenting role to their own satisfaction^(17,18). Also, parents think that if their children have a good awareness of their condition and its limitations, then this helps them because it reduces both their own and their child's anxiety and frustration^(31,34).

Mothers with physical or sensory impairments also say that planning and preparation is a successful coping strategy^(14,15,35). Mothers who engaged in extensive preparation regarding their children's safety, especially in the home, and their journeys outside of the home, felt less anxious about their children and more satisfied with their own role as a parent⁽¹⁵⁾. Some mothers have also found that support groups composed of other parents with the same impairments can be very helpful: the relationships provided by this type of group were considered to be extremely valuable by its members^(15,17,19,40,49).

A task force report on supporting disabled parents found that parents did not want their children labelled as "in need", but thought that their needs as a parent should be recognised and addressed by community care services⁽²⁰⁾. Parents also value direct payments because this allows them to arrange help to suit their own needs, rather than having to accept support from service providers that they

consider to be rigid and inflexible ⁽²⁰⁾. However, disabled parents also report that that they need more practical and financial help and support from services for the higher costs of parenting with a disability, especially with domestic issues such as heating, laundry, cleaning, child care, transport, going out with children, holidays, and adaptations to or equipment for the home ⁽¹⁶⁾. They also report great difficulty in accessing appropriate information, services and support ⁽¹⁶⁾. Parents with arthritis, and therapists working within the field, report that the referral system for statutory help can be slow and awareness of relevant sources of information can be limited ^(32,33). Parents and therapists have therefore requested that information about services and entitlements be made easily accessible, and eligibility made clear, and that it should also be made available in appropriate formats and locations ^(16,21,23,28,33). Some parents have said they would like more and better help from services but can be reluctant to seek it because they fear that their parenting may be seen or judged in a negative way ^(14,15,28,31,33) or because they are not aware of their entitlements ⁽²⁸⁾.

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

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 helplines working in the disability field, and contact information for local disability information services.

Disability, Pregnancy and Parenthood International

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

This organisation provides information to disabled parents and prospective parents, as well as relevant professionals and organisations, and promotes the networking of information and experience relating to pregnancy and parenthood for people with disabilities through a quarterly international journal. This organisation also co-ordinates the Deaf Parenting Project (<http://www.dppi.org.uk/deaf-parenting-group.html>), a group which meets regularly to look at ways of improving information and service provision for deaf parents.

Disabled Parents Network

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

The Disabled Parents Network (DPN) is a national organisation of, and for, disabled people who are parents or who hope to become parents, as well as their families, friends and supporters.

Joseph Rowntree Foundation

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

The Joseph Rowntree Foundation is one of the largest independent social policy research and development charities in the UK. It supports a wide programme of research and development projects in housing, social care and social policy. This includes work on supporting disabled parents perform their parenting role ⁽²⁰⁾.

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.

Social Exclusion Unit

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

The Social Exclusion Unit forms part of the Government's strategic multi-agency approach to tackling social exclusion.

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, and by improving and increasing access to child care.

Related SCARE briefings

Parenting Capacity and Substance Misuse

<http://www.elsc.org.uk/briefings/briefing06/index.htm>

The Health and Well-being of Young Carers

<http://www.elsc.org.uk/briefings/briefing11/index.htm>

Helping Parents with Learning Disabilities in their Role as Parents

<http://www.elsc.org.uk/briefings/briefing14/index.htm>

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>

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

2 **SCARE 14** (2005). Helping Parents with Learning Disabilities in their Parenting Role. Social Care Institute for Excellence. **Title link:**
<http://www.elsc.org.uk/briefings/briefing12/index.htm>

This is a research and policy briefing describing methods for helping parents with learning disabilities to perform their parenting role as well as possible.

3 **SCARE 6** (2004). Parenting Capacity and Substance Misuse. Social Care Institute for Excellence. **Title link:**
<http://www.elsc.org.uk/briefings/briefing06/index.htm>

This is a research and policy briefing describing methods for helping parents who have problems with drug and alcohol addiction.

4 **Barker L.T., Maralani V.** (1997). Challenges and Strategies of Disabled Parents: Findings from a National Survey of Parents with Disabilities. Oakland (CA), Berkeley Planning Associates.

This is a US survey of parents with disability.

5 **Katz P.P., Pasch L.A., Wong B.** (2003). Development of an instrument to measure disability in parenting activity among women with rheumatoid arthritis. *Arthritis & Rheumatism*, 48 (4), 935-943.

This study aims to develop a method of assessing and summarising parenting function and disability, and to use that method to describe parenting disability among a group of women with rheumatoid arthritis.

6 **Alexander C.J., Hwang K., Sipski M.L.** (2002). Mothers with spinal cord injuries: impact on marital, family, and children's adjustment. *Archives of Physical*

Medicine and Rehabilitation, 83 (1), 24-30.

This US study aims to evaluate how mothers with spinal cord injury (SCI) adjust to parenting, their marriages, and their families, and how their children adjust to their mothers' disability.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=11782828

7 **Wates M.** (2004). Righting the Picture: Disability and Family Life. In: Swain J., French S., Barnes C., Thomas C. (eds). Disabling Barriers - Enabling Environments. London, Sage, 135-141.

This article summarizes some of the key issues relating to disabled parents.

8 **Kelley S.D.-M., Sikka A., Venkatesan S.** (1997). A review of research on parental disability: Implications for research and counseling practice. Rehabilitation Counseling Bulletin, 41 (2), 105-121.

This US article reviews the research evidence on the influence of physical, cognitive and sensory disabilities on parenting.

A Critical Appraisal of this article is available

9 **SCARE 11** (2005). The Health and Well-Being of Young Carers. Social Care Institute for Excellence. **Title link:**

<http://www.elsc.org.uk/briefings/briefing11/index.htm>

This is a research and policy briefing describing how young carers may be affected by their role and what interventions they find helpful.

10 **Stickland H.** (2003). Disabled Parents and Employment. London, Department of Work and Pensions.

This paper considers the link between disabled families, social exclusion and poverty.

11 **Woodhouse A.** (1997). Parents with learning disabilities: does everyone have the right to have children? Journal of Learning Disabilities for Nursing, Health, Social Care, 1141-146.

This is a review of literature on the topic of parenting by parents with learning disabilities.

12 **Gordon D., Townsend P., Levitas R., Pantazis C., Payne S., Patsios D. et al.** (2000). Poverty and Social Exclusion in Britain. York, Joseph Rowntree Foundation.

This is a national survey examining poverty and social exclusion in Britain.

13 **Department for Work and Pensions** (2003). Opportunity for All. Department for Work and Pensions. **Title link:** <http://www.dwp.gov.uk/ofa/reports/2003/>

This is the fifth annual report of the DWP.

14 **Grue L., Laerum K.T.** (2002). 'Doing motherhood': some experiences of mothers with physical disabilities. *Disability and Society*, 17 (6), 671-683.

This Norwegian study interviews thirty mothers with physical disabilities about their experiences as a parent.

A Critical Appraisal of this article is available

15 **Conley-Jung C., Olkin R.** (2001). Mothers with visual impairments who are raising young children. *Journal of Visual Impairment and Blindness*, 95 (1), 14-29.

This US study explores the views of mothers with visual impairment. The mothers' key concerns are reported to be their children's safety; the extra time needed to accommodate the impairment; transportation; and handling the reactions of others.

A Critical Appraisal of this article is available

16 **Preston G.** (2005). *Family Values: Disabled Parents, Extra Costs and the Benefits System*. London, Disability Alliance.

This is a report on the additional costs of parenting faced by parents with a disability.

17 **Grant M.** (2001). Mothers with arthritis: child care and occupational therapy: insight through case studies. *British Journal of Occupational Therapy*, 64 (7), 322-329.

This is a small-scale qualitative study examining the physical problems experienced by parents with arthritis.

A Critical Appraisal of this article is available

18 **Farber R.S.** (2000). Mothers with disabilities: in their own voice. *American Journal of Occupational Therapy*, 54 (3), 260-268.

This US qualitative study seeks to gain an understanding of the personal experience of women with disabilities as mothers and in relation to their social and family environment.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_ui

[ds=10842682&dopt=Abstract](#)

A Critical Appraisal of this article is available

19 **Smith S.R., Soliday E.** (2001). The effects of parental chronic kidney disease on the family. *Family Relations: Interdisciplinary Journal of Applied Family Studies*, 50 (2), 171-177.

This is a US qualitative study on the effects of a parent's chronic kidney disease on their family.

A Critical Appraisal of this article is available

20 **Morris J.** (2003). The Right Support: Report of the Task Force on Supporting Disabled Adults in their Parenting Role. Joseph Rowntree Foundation. **Title link:** <http://www.jrf.org.uk/knowledge/findings/socialcare/963.asp>

This document reports on the findings of a Task Force on Supporting Disabled Adults in their Parenting Role. This Task Force received evidence that people with physical disabilities, sensory impairments, learning disabilities, mental health difficulties, long-term illness and HIV/AIDS experience common barriers to receiving appropriate support in their parenting role.

21 **Wates M.** (2003). It shouldn't be down to luck. Disabled Parents Network.

Title link:

<http://www.disabledparentsnetwork.org.uk/Resources/M%20Wates.htm>

This report gives the results of a consultation with disabled parents.

22 **Olsen R., Wates M.** (2003). Disabled Parents. Examining Research Assumptions. *Research In Practice.* **Title link:**

<http://www.rip.org.uk/publications/researchreviews.asp>

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.

23 **Wates M.** (2002). Supporting disabled adults in their parenting role. Joseph Rowntree Foundation. **Title link:**

<http://www.jrf.org.uk/knowledge/findings/socialcare/422.asp>

This document reports on a survey to find out whether social services departments have policies/protocols for providing services to parents with physical and sensory impairments and/or learning disabilities and, if so, to see how effective these are likely to be in meeting the needs of families.

24 **Gooding S.** (2000). A Jigsaw of Services: Inspection of services to support disabled adults in their parenting role. Department of Health. **Title link:**

http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsInspectionReports/PublicationsInspectionReportsArticle/fs/en?CONTENT_ID=4005103&

[chk=hgrdpj](#)

This is the national strategy document for supporting disabled parents.

25 **Becker S., Dearden C., Aldridge J.** (2001). Young Carers in the UK: research, policy and practice. Research, Policy and Planning. **Title link:** <http://www.elsc.org.uk/socialcareresource/rpp/articles/1822000art3.htm>

This article reviews the main research studies on young carers in the UK, examines the services available to support young carers, and identifies the implications for future policy and practice, particularly in social care.

26 **Bond H.** (2000). Learning how to cope. Community Care. **Title link:** [http://www.communitycare.co.uk/articles/article.asp?liarticleid=5176&liSectionID=22&sKeys="learning+how+to+cope"&liParentID=26](http://www.communitycare.co.uk/articles/article.asp?liarticleid=5176&liSectionID=22&sKeys=)

This article reports on a South London project to help parents with learning disabilities

27 **Wade M.I., Foster N.E., Cullen L.A., Barlow J.H.** (1999). Advising mothers with arthritis. Breast and bottle feeding for mothers with arthritis and other physical disabilities. Professional Care of Mother and Child, 9 (2), 35-38.

This article makes recommendations on how health professionals can support new mothers with arthritis.

28 **Harris J., Bamford C.** (2001). The uphill struggle: services for deaf and hard of hearing people - issues of equality, participation and access. Disability and Society, 16 (7), 969-979.

This article focuses on the social exclusion experienced by deaf adults, including their role as parents.

A Critical Appraisal of this article is available

29 **Tracey B.L.** (2002). Silent Partners? The problem for deaf parents in accessing appropriate information and support from Health, Education and Social Services for themselves and their (predominantly) hearing children. University of Bristol, School for Policy Studies.

This is an M.Phil thesis (Unpublished).

30 **Jones E.G.** (1995). Deaf and hearing parents' perceptions of family functioning. Nursing Research, 44 (2), 102-105.

This US study compares the perceptions of deaf and hearing parents about their family life.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=7892135&dopt=Abstract

A Critical Appraisal of this article is available

31 **Barlow J.H., Cullen L.A., Foster N.E., Harrison K., Wade M.** (1999). Does arthritis influence perceived ability to fulfil a parenting role? Perceptions of mothers, fathers and grandparents. *Patient Education and Counseling*, 37 (2), 141-151.

This study aims to examine the realities of parenting from the perspective of mothers and fathers with arthritis. The consensus of the study group is that pain, fatigue and restricted physical functioning combine to interfere with their parenting role.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=14528541

A Critical Appraisal of this article is available

32 **Foster N.E., Wade M.I., Harrison K., Barlow J.H.** (1998). Being a parent with arthritis: the therapists viewpoint. *Journal of Interprofessional Care*, 12 (4), 437-440.

This study explores the views of therapists involved in supporting parents with arthritis and reports their recommendations to help these adults in their parenting role.

A Critical Appraisal of this article is available

33 **Foster N.E., Wade M.I., Harrison K., Barlow J.H.** (1999). Focusing on arthritis and parenting. *British Journal of Therapy and Rehabilitation*, 6 (7), 347-353.

This is a small-scale study designed to gain understanding of the experience of parents who have arthritis, from the perspectives of the occupational therapists and physiotherapists involved in their care.

A Critical Appraisal of this article is available

34 **Mens-Verhulst J., Radtke H.L., Spence C.D.** (2004). The private struggle of mothers with asthma: a gender perspective on illness management. *Patient Education & Counseling*, 54 (1), 79-86.

This joint Canadian-Dutch qualitative study conducts interviews with a small sample of mothers with asthma to explore their experiences of parenting.

A Critical Appraisal of this article is available

35 **McKeever P., Angus J., Lee-Miller K., Reid D.** (2003). "It's more of a production": accomplishing mothering using a mobility device. *Disability and*

Society, 18 (2), 179-197.

This is a qualitative study conducted by Canadian researchers examining the experiences of mothers who use wheelchairs and its impact on their parenting role.

A Critical Appraisal of this article is available

36 **Tuleja C., DeMoss A.** (1999). Baby care assistive technology. *Technology and Disability*, 11 (1, 2), 71-78.

This is a US study examining the value of equipment to help disabled mothers in their parenting of very young children.

37 **Reid D., Angus J., McKeever P., Miller K.L.** (2003). Home is where their wheels are: experiences of women wheelchair users. *American Journal of Occupational Therapy*, 57 (2), 186-195.

This US paper examines the experiences of mothers who are wheelchair users in their roles of homemaking and parenting.

A Critical Appraisal of this article is available

38 **Banks P., Cogan N., Deeley S., Hill M., Riddell S., Tisdall K.** (2001). Seeing the invisible children and young people affected by disability. *Disability and Society*, 16 (6), 797-814.

This paper reports on two studies examining the role performed by young carers and its impact on their lives.

A Critical Appraisal of this article is available

39 **Newman T.** (2002). 'Young carers' and disabled parents: Time for a change of direction? *Disability and Society*, 17 (6), 613-625.

This paper reviews and critically examines research on young carers.

40 **Kirshbaum M.** (2000). A disability culture perspective on early intervention with parents with physical or cognitive disabilities and their infants. *Infants and Young Children*, 13 (2), 9-20.

This US article considers the views of disabled parents regarding interventions to help them in their parenting of very young children.

41 **Woodhouse A., Green G., Davies S.** (2001). Parents with learning disabilities: service audit and development. *British Journal of Learning Disabilities*, 29 (4), 128-132.

This paper reports on an audit and service model for delivering parenting support to parents with learning disabilities.

42 **Dearden C., Becker S.** (2000). Growing Up Caring: Vulnerability and Transition to Adulthood - Young Carers' Experience. Joseph Rowntree Foundation. **Title link:**

<http://www.jrf.org.uk/knowledge/findings/socialpolicy/630.asp>

This study examines the extent to which caring can influence young people's decisions and activities in relation to education, training and employment, leaving home and becoming an adult. It also looks at the impact of community care policies and services on these young people.

43 **Dearden C., Becker S.** (1998). Young Carers in the United Kingdom: A Profile. London, Carers' National Association.

This is an extensive survey of young carers.

44 **Centre for Child and Family Research.** (2002). Children caring for parents with severe and enduring mental illness. Loughborough, Loughborough University.

This is a report of a 2-year study looking at the experiences and needs of children who care for a parent with mental illness.

45 **Keith L., Morris J.** (1995). Easy targets: a disability rights perspective on the "children as carers" debate. *Critical Social Policy*, 44/45, 36-57.

This paper challenges the construction of the concept of 'young carers' employed by researchers and policy-makers.

46 **Olsen R.** (1996). Young carers: challenging the facts and politics of research into children and caring. *Disability and Society*, 11 (1), 41-54.

This paper reviews and critically examines research on young carers.

47 **Booth T., Booth W.** (1999). Parents together: action research and advocacy support for parents with learning difficulties. *Health and Social Care in the Community*, 7 (6), 464-474.

This paper summarises the findings of the research project reported in the book "Advocacy for Parents with Learning Difficulties: Developing Advocacy Support", by the same authors.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11560663&dopt=Abstract

48 **Kirshbaum M., Olkin R.** (2002). Parents with physical, systemic, or visual disabilities. *Sexuality and Disability*, 20 (1), 65-80.

This US article reviews the problems experienced by parents with physical disabilities and impairments.

49 **Jones A., Jeyasingham D., Rajasooriya S.** (2004). Invisible Families: the Strengths and Needs of Black Families in which Young People have Caring Responsibilities. Joseph Rowntree Foundation. **Title link:**
<http://www.jrf.org.uk/knowledge/findings/socialcare/412.asp>

This study investigates the experiences and needs of young black people caring for disabled or ill family members and their access to services.