

Date of Briefing – February 2005

Helping parents with learning disabilities 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 and supporting parents with learning disabilities, negative attitudes about parents with learning disabilities, and tendencies to pass responsibility between children's and adults services.
- Parent training programmes for parents with learning disabilities focus on child care, child safety, and mother-child interaction. The results of research into the effectiveness of these programmes are inconclusive. However, home-based programmes do demonstrate some success and are preferred to "centre-based" programmes as a form of education.
- The research has found a strong association between supportive social networks and the positive psychological well-being of parents with learning disabilities, but there is no research to demonstrate that such support networks have a beneficial effect on their parenting.
- Parents with learning disabilities report positive attitudes towards self determination in initiatives to support them in their parenting. They also request that information about services and entitlements be made accessible in appropriate formats and locations.

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 intellectual or learning disabilities and the support they may need to help them as parents. The extent to which a parent's intellectual impairment will have a negative effect on their parenting has been hotly contested. However, it is not the aim of this briefing to weigh up the arguments in any detail. 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 learning disabilities encounter many of the same social and organisational barriers as parents with other forms of disability or impairment. However, this briefing aims to bring together medical and social elements in a single document, and to address some of the specialist requirements of parents with learning disabilities.

This briefing is concerned only with summarising the policy, guidance and research literature on how parents with learning disabilities may be supported in their efforts to provide the best possible type of parenting for their children. This briefing is therefore "parent-centred", but may be read in conjunction with the briefing on young carers, which is "child-centred" ⁽²⁾, as well as the briefing on parenting by parents with physical or sensory impairments ⁽³⁾. In combination, these briefings hopefully offer a balanced examination of the topic.

Why this issue is important

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

Parents with learning disabilities often need to overcome preconceived ideas among other people about their ability to parent. For example, there may be a willingness to attribute potential difficulties they may have parenting to their impairment rather than to disabling barriers or to other factors that affect the parenting of all parents. This has been described as the "presumption of incompetence": the "absence of explicit standards and the uncertain nature of the

links between parental competence and child outcomes render parents with learning difficulties vulnerable to discrimination”⁽⁴⁾. However, it is also recognised that this group are more likely to require financial, practical and social support if they are to perform their parenting role as effectively as they want⁽⁵⁻⁸⁾. Although it is known that there are 2.1 million disabled parents in the United Kingdom⁽⁹⁾, actual numbers of parents with learning disabilities are unknown, which means there is a lack of concrete information with which to inform the development and planning of relevant services. 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”⁽¹⁰⁾.

Several factors have been demonstrated to have an adverse effect on parenting: these include low socio-economic status; unemployment; and social isolation or exclusion⁽¹¹⁻¹⁴⁾. All of these factors make parenting difficult, and parents with intellectual or learning disabilities are at greater risk of experiencing one or more of these disadvantages than other groups. Many parents with learning disabilities are unemployed, on low incomes and rely very heavily on benefits and statutory services⁽¹⁵⁻¹⁷⁾; many are single mothers⁽¹⁸⁾; and few have the same opportunities for “informal social learning” from friends and extended family as non-disabled parents⁽¹⁵⁾. The failure to receive sufficient and appropriate support from services can adversely affect both the parent and their children⁽¹⁹⁾. Parents with learning disabilities therefore often experience social exclusion^(6,16,17,20).

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 parents with intellectual or learning disabilities.

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.

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 document states that the Department of Health is to work with Sure Start and the National Family and Parenting Institute "to ensure that the needs of parents with learning disabilities are recognised".

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".

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.hms0.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.hms0.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.hms0.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.hms0.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.hms0.gov.uk/acts/acts1989/Ukpga_19890041_en_1.htm

This Act does not assume that children are "in need" simply because a parent has learning disabilities. 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 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.

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 effect ⁽²¹⁾.

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 the input of parents into the development of services. A four-level strategy has also been developed to respond to the parenting needs of parents with learning disabilities. This involves the inclusion of parenting as a specific need to be addressed by a local

learning disabilities service, and the training of health and social care professionals who work with parents with learning disabilities and their families on how to assess the parenting needs of such parents ⁽¹¹⁾. An audit of the strategy demonstrated that professionals became more aware of issues of assessment, and that it was feasible to include parenting needs within the remit of existing services, although a specialised parenting service for parents with learning disabilities was recognised as the ideal ⁽¹¹⁾. It has been suggested that this strategy could be implemented locally within a framework which makes use of both adult and children's services ⁽²³⁾.

Greater co-operation between adults' and children's services is a key element of much of the research and policy literature ^(5,10,11,13,18,22,24-27) as is a specific assessment of parenting needs ^(13,19,24,26,27) and the involvement of disabled parents in the development of policy ^(11,18,21,22,24).

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.

Gooding 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.

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.

Several local projects and initiatives have examined possible approaches to supporting parents with learning disabilities in their parenting role, either directly or indirectly. A south London initiative developed a multi-agency approach which used repetition of practical examples in the home to teach parenting skills, such as providing meals for children ⁽²⁷⁾. It also aimed to train health and social care professionals in how to assess the needs of parents with learning disabilities, and how the different groups of professionals could provide support to such parents. Another study reported on an attempt by a local service to co-ordinate adult and children's services in the delivery of support to parents with learning disabilities ⁽⁶⁾. This study identified practical problems of developing such a multi-agency service, including limited mutual awareness and appreciation of the different services, their knowledge and roles, and lack of funding and appropriate training.

Parents Together was a project designed to address environmental pressures on parents with learning disabilities, such as unemployment, bad housing and debt, rather than teaching specific parenting skills ⁽¹⁸⁾. The intention was to free-up time and resources for these parents to concentrate on parenting. The project set up support groups to enable the development of social skills and networks, and provided advocates to guide parents, provide information and make them aware of services. In all cases, a high level of self-determination remained with the parents involved. Parents felt empowered by the advocates and support groups and their own self-management role. The advocates were considered to give valuable support, but were unable to affect significantly the environmental pressures on the parents. This was attributed in part to the absence of family-centred services for parents with learning disabilities. The provision of such support by non-statutory services was welcomed by the parents who chose to be involved ⁽⁷⁾. A Supported Learning Project (SLP) for mothers with learning disabilities also focused on enhancing the participants' self-advocacy and self-help skills through a support group and received positive feedback from the mothers involved ⁽²⁸⁾. This group again offered a high level of flexibility, self-determination and responsiveness to its participants.

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

The research literature on parenting by people with learning disabilities focuses principally on mothers, either principally or exclusively ^(11,14,16,17,20,29). Parents generally, and fathers especially, are much less well represented in the literature ^(15,18,21,23,24,27,30). The focus on mothers in the research is because "they are typically their children's primary or exclusive caregivers" ⁽²⁰⁾. It has been reported

that fathers with learning disabilities may not be assessed for support of any kind to help them understand their parenting role, if their partner does not have learning disabilities⁽²³⁾. Also, the research focuses on very young children, up to school age, so the changing role of the parent as children grow up is not reflected well in the literature. All of the studies reported here offer original insights into the topic, but there are some particularly good studies^(6,15-17,29,31). The type of weaknesses which affect the research include a lack of detail on method, data collection and analysis^(13,30,32). These limitations need to be taken into account when considering the research findings set out below. It is important to stress that the research described here looks at the experiences of parents primarily in terms of the specialist requirements generated by their learning disability, and the barriers they face as a direct result of this, rather than examining the broader social barriers encountered by disabled parents.

Which interventions have been found to be effective in supporting the parenting role of parents with learning disabilities?

Parent training programmes are often developed for parents with learning disabilities, and evaluation of their effectiveness is a common subject of the research^(14,15,29-31,33,34). Most parent training programmes tend to focus on child care, child safety, and mother-child interaction. However, the results of research into parent training programmes aimed at parents with learning disabilities are inconclusive. The research points out that the generalisable nature of what is being taught to parents is very important, in other words, that the parent can take what they have learned and apply it to real world situations and to instances beyond the examples used in training^(14,16). The most effective and potentially generalisable type of parent training for parents with learning disabilities is education undertaken in the home^(14,15,30,31). Home-based programmes do demonstrate some success and are known to be preferred over “centre-based” programmes as a form of education^(30,31,34), but many such interventions may not be particularly effective. For example, the home environment may offer too many distractions; and parents with learning disabilities who live with their own parents or other family members may not have sufficient personal control over their domestic environment and the parenting of their children to apply what they have learned^(14,17,24,30).

Teaching which is delivered only verbally, or based on observation or hypothetical situations can prove inaccessible to parents with learning disabilities⁽²⁷⁾. Information and training has been found to be most effective when it is tailored to the abilities of individual parents^(24,26). The most effective forms of education are interactive, practical, involve repetition or “reinforcement”, and use pictorial materials^(14,15,29,30). However, parents with learning disabilities can find too much repetition both boring and condescending⁽³⁰⁾. Self-learning manuals are also effective for teaching child care and child safety skills to parents with learning disabilities; they offer a “minimal involvement”, low-cost, home-based alternative to the more systematic, professionally-led parenting programmes⁽²⁹⁾.

This enables the parents to retain a sense of control and self-help in the learning process. Services and training programmes should be developed in conjunction with parents and their advocates ^(6,11,21,24,33) and training and support should be as non-intrusive as possible and allow parents to retain a sense of self-help and control ^(6,7,11,18,27,28).

What is the role of social support systems in helping parents?

The research has found a strong association between supportive social networks and the positive psychological well-being of parents with learning disabilities ^(15,16). Some parents with learning disabilities have said that they like support groups because they give them confidence, improve their self-esteem and assertiveness, and enhance feelings of control ^(15,28). Such groups can act as a social support network, which is often missing from the lives of parents with learning disabilities. It has been argued that the improved confidence and sense of well-being engendered by an increased sense of self-worth among these parents may positively affect parenting ⁽¹⁵⁾. Social support networks may also be important because families and others can provide practical help, such as child care and taking children out: parenting therefore is not carried out in isolation ^(6,16). Social support networks may also have an indirect effect on parenting experience because parents have a greater network of people with whom to share experiences, concerns and solutions; this has been described as “informal social learning” ^(15,16). Such social support is often lacking for parents with learning disabilities ^(6,16,17,20). Measures to develop social skills and expand social networks can therefore be an important part of a “family-centred” approach to supporting parents with intellectual or learning disabilities ⁽¹⁶⁾. However, there is currently little direct or indirect evidence to demonstrate that increased self-esteem, confidence or more extensive social networks have a positive effect on the parenting of parents with learning disabilities; specific research has yet to be done on this topic ^(15,20).

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

A review of the research into parents with learning disabilities found that different parents had different needs: parents with learning disabilities require specialist support services ⁽¹⁹⁾. However, it is questionable whether health and social services are always in a position to provide this support ⁽¹⁹⁾; there is currently little specialist provision to parents with learning disabilities ⁽³⁵⁾. One barrier to the provision of effective parent training is the division and blurring of responsibilities between adults’ and children’s services ^(5,21,24,25). 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 adults with learning disabilities. The needs of parents with learning disabilities 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” ⁽¹¹⁾. It has also been found that the needs of parents with learning disabilities are only identified and assessed

when a crisis is reached and there is a potential issue of child protection ^(21,24). The legislative framework and the research and policy literature therefore acknowledge that parents with learning disabilities should be able to access support from adult community care services, and that both adults' and children's services need to work together to ensure that work is available at an early stage ^(13,18,27). The potential barriers to the development and maintenance of such specialised and/or multi-agency services for parents include limited funding, lack of skills among professionals for assessing and supporting parents with learning disabilities, and entrenched attitudes about the responsibilities of respective services towards children and adults ^(5,11,19). Parents with learning disabilities can also be reluctant to approach statutory services for support because they fear potentially negative evaluations of their parenting if they seek help ^(7,36).

Information needs for professionals working within this field include tools for assessing parental competence; knowing how to access resources and services to support parents; and knowing how best to teach practical parenting skills to parents with learning disabilities ^(11,13,19,27). One study found that community nurses do not feel they have sufficient training to assess the needs of parents with learning disabilities or to provide appropriate support to them ⁽¹³⁾. The assessment of a parent's learning difficulties is a necessary and important step because it determines the level of support from statutory agencies. For example, parents categorised as having "mild to moderate learning difficulties" do not qualify for support from adult learning disabilities services ^(24,26). Assessment is also necessary to ascertain the ability of a parent to understand any help they receive to support their parenting ^(27,36); support and education must be based on individual assessment and personalised to the needs and ability of the parent ⁽¹⁹⁾. Multi-agency working needs to be very carefully structured and co-ordinated to promote consistency and continuity of information and services between the many professionals involved ⁽¹³⁾.

User & Carer Knowledge

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

Some parents with learning disabilities have said that they like support groups because they give them confidence, improve their self-esteem and assertiveness, and enhance feelings of control ^(15,28). Such groups can act as a social support network, which is often missing from the lives of parents with learning disabilities ⁽⁶⁾. Parents have also said that such groups offer them "a break" and are a source of social interaction and mutual support ⁽²⁸⁾. Social support networks can potentially be more inhibiting than helpful, however, for example, other family members may take over most or all of the parenting tasks,

thus limiting their opportunity to perform their role as a parent ^(6,17,30). The same problem can apply to the services provided by statutory agencies ⁽¹⁸⁾. Parents have also said they can be reluctant to seek support from individuals or services who give them advice without being asked because they feel this suggests the people involved lack confidence in their abilities to parent ⁽⁶⁾.

Parents with learning disabilities have positive attitudes towards self-determination and self-help in their development and choices as parents, as well as towards clarity in the communication of information about their needs and the services that are available to them ^(18,21,24,28). In a consultation with nine parents (6 mothers and 3 fathers) with learning disabilities undertaken for this briefing, parents preferred face to face contact with social workers and others rather than telephone conversations or written information, where the language could be quite legal and difficult to understand. Some of the parents consulted for this briefing also reported that they had been on parenting courses but did not find them particularly useful. Parents agreed to attend these courses as a package of care to keep their children living with them, but this desired parental outcome was not achieved.

Both the local consultation undertaken for this briefing and the research literature more generally report a reluctance among parents with learning disabilities to deal with social services because of concerns about negative or subjective judgments of their parenting and because of fears that their children may be taken away from them ^(7,18,19,21). Contacts with social services are therefore characterised by poor communication, suspicion and mistrust. Parents also reported in the consultation exercise that they would like the support of advocates or individuals, whom they see as “neutral”, to help them in their dealings with social services. Parents also feel that social services focus too much on the child and not enough on the parents or family as a whole, and only become involved when a crisis is reached. This has also been reported by the research ⁽²¹⁾. Parents consulted for this briefing also reported that they felt they did not get enough support from specialist or general services to help them keep their children or to help them if their children were removed.

The experience of the parents in the local consultation was that their children were removed from their care. The parents thought that they would be better able to cope with this distressing situation if they had regular and frequent contact with their children, and were supported in coming to terms with their changed circumstances.

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.

Change

<http://www.changepeople.co.uk/index.html>

This is an organisation run by disabled people. It makes available a guide on "You and Your Baby"

http://www.changepeople.co.uk/documents/YYB_Flyer_000.pdf

for parents with learning disabilities.

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.

Circles Network

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

The Circles Network is a voluntary organisation that works with vulnerable people, especially those with learning disabilities. They work with parents with learning disabilities as part of the Crowley House Project.

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.

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.

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.

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.

Supported Parenting for mothers and fathers with learning difficulties

<http://www.supported-parenting.com/>

This website includes information on certain publications on parenting by people with learning disabilities, practice points derived from research, and a section of useful links.

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 Physical or Sensory Impairments in their Role as Parents

<http://www.elsc.org.uk/briefings/briefing13/index.htm>

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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 11** (2005). The Health and Well-Being of Young Carers. Social Care Institute for Excellence (SCIE). **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.

3 **SCARE 13** (2005). Helping Parents with a Physical Disability or Impairment in their Parenting Role. Social Care Institute for Excellence (SCIE). **Title link:**

<http://www.elsc.org.uk/briefings/briefing13/index.htm>

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

4 **Booth T., Booth W.** (1996). Parental competence and parents with learning difficulties. Child and Family Social Work, 1 (2), 81-86.

This paper questions the presumption of incompetence that is often applied to disabled parents.

5 **McBrien J., Power M.** (2002). Professional attitudes to supporting parents with learning disabilities. Tizard Learning Disability Review, 7 (3), 16-22.

This article describes an audit, training and evaluation which highlights some of the underlying difficulties, particularly differences in attitudes and approach between health and social services staff that can obstruct joint working and effective practice in providing support to parents with learning disabilities.

6 **Llewellyn G.** (1995). Relationships and social support: views of parents with mental retardation/intellectual disability. Mental Retardation, 33 (6), 349-363.

This Australian qualitative study explores the views of parents with intellectual disability about their relationships and the social support for their parenting.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8569485&dopt=Abstract

A Critical Appraisal of this article is available

7 **Booth W.** (2000). Parents with learning disabilities need support. *Nursing Times*, 96 (23), 41.

This article describes the value of the parent-led support groups as part of the Parents Together project summarised in Booth & Booth 1999.

8 **Booth T., Booth W.** (1998). *Growing Up with Parents Who have Learning Difficulties*. London, Routledge.

This study interviews thirty now-adult children to explore their experiences of being brought up in a family headed by a parent or parents with learning disabilities.

9 **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.

10 **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.

11 **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.

12 **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.

13 **Culley L., Genders N.** (1999). Parenting by people with learning disabilities: the educational needs of the community nurse. *Nurse Education Today*, 19 (6), 502-508.

This article discusses some of the findings of a research project which was designed to examine the role of community learning disability nurses in supporting people with learning disabilities who become parents.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10693499&dopt=Abstract

A Critical Appraisal of this article is available

14 **Hur J.** (1997). Review of research on parent training for parents with intellectual disability: methodological issues. *International Journal of Disability, Development and Education*, 44 (2), 147-162.

This is a review of the methods and results of research into parent training programmes for parents with learning difficulties.

A Critical Appraisal of this article is available

15 **McGaw S., Ball K., Clark A.** (2002). The effect of group intervention on the relationships of parents with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15 (4), 354-366.

This study seeks to assess the effectiveness of group training in improving the self-concept and relationships of parents with learning disabilities, including the relationships with their children.

A Critical Appraisal of this article is available

16 **Kroese B.S., Hussein H., Clifford C., Ahmed N.** (2002). Social support networks and psychological well-being of mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15 (4), 324-340.

This study investigates the impact of the social support networks of mothers with intellectual disabilities on their psychological well-being and views of parenting.

A Critical Appraisal of this article is available

17 **Llewellyn G., McConnell D., Cant R., Westbrook M.** (1999). Support network of mothers with intellectual disability: an exploratory study. *Journal of Intellectual and Developmental Disability*, 24 (1), 7-26.

This Australian study records the characteristics of social support networks of mothers with learning disabilities.

A Critical Appraisal of this article is available

18 **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

19 **McGaw S.** (2000). What Works for Parents with Learning Disabilities?

Barnardos. **Title link:**

http://www.barnardos.org.uk/resources/researchpublications/documents/WWPA_RWLD.PDF.

This report draws on research and empirical evidence to establish a knowledge base for practitioners and policy-makers working with and for parents with learning disabilities.

20 **Feldman M.A., Varghese J., Ramsay J., Rajska D.** (2002). Relationships between social support, stress and mother-child interactions in mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15 (4), 314-323.

This study examines the relationships between parenting stress, social support and mother-child interactions in thirty mothers with intellectual disabilities.

A Critical Appraisal of this article is available

21 **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.

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 **O'Hara J., Martin H.** (2003). Parents with learning disabilities: a study of gender and cultural perspectives in east London. *British Journal of Learning Disabilities*, 31 (1), 18-24.

This study seeks to evaluate service provision for two culturally different groups of parents with learning disabilities, and to compare these two groups on culture and gender issues.

A Critical Appraisal of this article is available

24 **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 impairments, sensory impairments, learning disabilities, mental health difficulties, long-term illness and HIV/AIDS experience common barriers to receiving appropriate support in their parenting role.

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 **Shearn N.** (2001). Too dependent on services. Community Care. **Title link:** [http://www.communitycare.co.uk/articles/article.asp?liarticleid=33470&liSectionID=22&sKeys="Too+dependent+on+services"&liParentID=26](http://www.communitycare.co.uk/articles/article.asp?liarticleid=33470&liSectionID=22&sKeys=)

This article describes a case study concerning a parent with learning disabilities who is experiencing problems parenting.

27 **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 difficulties.

28 **Booth T., Booth W.** (2003). Self-advocacy and supported learning for mothers with learning difficulties. Journal of Learning Disabilities, 7 (2), 165-193.

This article describes a supported learning project (SLP) in Sheffield for 31 mothers with learning disabilities.

29 **Feldman M.A., Case L.** (1999). Teaching child-care and safety skills to parents with intellectual disabilities through self-learning. Journal of Intellectual and Developmental Disabilities, 24 (1), 27-44.

This study evaluates the efficacy of self instructional audiovisual child care and safety manuals for parents with learning difficulties.

A Critical Appraisal of this article is available

30 **Llewellyn G., McConnell D., Russo D., Mayes R., Honey A.** (2002). Home-based programmes for parents with intellectual disabilities: Lessons from practice. *Journal of Applied Research in Intellectual Disabilities*, 15341-353.

This Australian study evaluates the implementation of a randomized trial of a home-based parent education programme for parents with intellectual disabilities. A Critical Appraisal of this article is available

31 **Llewellyn G., McConnell D., Honey A., Mayes R., Russo D.** (2003). Promoting health and home safety for children of parents with intellectual disability: a randomized controlled trial. *Research in Developmental Disabilities*, 24 (6), 405-431.

This Australian randomised controlled trial evaluates the efficacy of a home-based intervention targeted at parents with learning disabilities to promote the health and safety of pre-school children.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=14622893&dopt=Abstract

32 **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 nature of the role performed by young carers and its impact on their lives.

A Critical Appraisal of this article is available

33 **Heinz L.C., Grant P.R.** (2003). A process evaluation of a parenting group for parents with intellectual disabilities. *Evaluation and Program Planning*, 26 (3), 263-274.

This Canadian study evaluates a specialised parent training programme for parents with learning disabilities.

34 **Armstrong K., Fraser J.A., Dadds M.R., Morris J.** (2000). Promoting secure attachment, maternal mood and child health in a vulnerable population: a randomized controlled trial. *Journal of Paediatric Child Health*, 36 (6), 555-562.

This paper evaluates the efficacy of an early home-based intervention on the quality of maternal-infant attachment, maternal mood and child health in a cohort of families assessed as vulnerable.

Abstract available

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11115031&dopt=Abstract

35 **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.

36 **Richardson N.** (2001). When parents have learning difficulties. Nursing Times, 97 (26 April), 40-41.

This brief discussion paper describes the type of support that can be helpful for parents with learning disabilities.