



Supporting disabled parents

A family or a fragmented approach?

February 2009

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- put the people who use social care first;
- improve services and stamp out bad practice;
- be an expert voice on social care; and
- practise what we preach in our own organisation.

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Executive summary

1. This CSCI report seeks to examine the experiences of disabled parents and their families and to see how far council policies, services and practice are providing appropriate support.
2. Councils have responsibilities under current policy both to support disabled parents who have children and to support children who assist their disabled parents. This was policy before the separation of adults' and children's services, but since then competition between departments as to who 'owns' the issues of the family has escalated. As a consequence, families can feel in a situation where they are out of control. This report looks at how councils balance these two responsibilities and the subsequent experiences of disabled parents and their families.
3. Existing evidence has already raised concerns about the extent to which disabled parents' needs have been identified and responded to, particularly in the light of the recent structural separation within councils of adults' and children's services. Guidelines developed by the Social Care Institute for Excellence (SCIE) have provided councils with a framework for developing strategies and delivering appropriate support to disabled parents and their families and a benchmark for good practice, which this report uses to assess progress.
4. Given this policy context, this CSCI report has been aligned closely with work currently being undertaken by the Office for Standards in Education, Children's Services and Skills (Ofsted) on young people providing support to their parents.
5. Disabled parents' are a diverse group of people including those parents with physical and/or sensory impairments; learning disabilities; mental health needs; drug- and alcohol-related problems; long-term medical conditions, such as living with HIV; and parents who identify as part of the Deaf community. It is important to recognise that some parents with additional support requirements relating to impairment may not identify as 'disabled parents'. Others may resist being described as such as they fear it may lead to inappropriate interventions in their lives. It has been estimated that there

are 1.1 million households with dependent children that have at least one disabled parent¹.

6. This report is based on the social model of disability, which focuses on the barriers that disabled individuals experience, including attitudes towards disabled people, rather than focusing solely on people's impairments. The social model approach underpins current government strategy on improving the life chances of disabled people and the public sector legal duty to promote disability equality. It is also the approach taken by the Disabled Parents Network (DPN)².
7. The findings in this report are taken from a national survey of 50 councils; of the 70 interviews, 36 were conducted with representatives of adults' services and 32 of children's services, and two were conducted with a representative from each service jointly. To supplement the national picture, in-depth study workshops of services were conducted in four council areas.

Policy context

8. Policy and practice have largely been developed separately within adults' and children's services, where each has looked at the support needed through their particular lens rather than taking a 'whole-family' approach. There has long been long standing concern about the 'gap' created between services through which disabled parents and their families can fall, particularly with the separation of adults' and children's services.
9. However, recent policy developments offer opportunities to address these problems. These include:
 - the *Putting people first* concordat, which emphasises maximising the ways people can direct their own support³
 - the *Think family* policy, where inter-agency working, including between adults' and children's services, is the key to adopting a family approach^{4, 5}.

1 Social Care Institute for Excellence (2006) *Supporting disabled parents and parents with additional support needs*. London: Social Care Institute for Excellence.

2 Disabled Parents Network (www.disabledparentsnetwork.org.uk).

3 Her Majesty's Government Ministerial Concordat (2007) *Putting people first. A shared vision and commitment to the transformation of adult social care*. London: Department of Health.

4 Cabinet Office Social Exclusion Task Force (2007) *Reaching out: think family*. London: Cabinet Office.

5 Cabinet Office (2008) *Think family: improving the life chances of families at risk*. London: Cabinet Office.

10. The Human Rights Act 1998 (upholding the right to respect for private and family life), the Disability Discrimination Act 2005 and other equality legislation should underpin work to support disabled parents. Guidance on Fair Access to Care Services⁶ also reinforces the importance of supporting people in their parental roles.

Disabled parents' and families' experiences and views

11. Parents are part of families and families are part of communities; support should be provided at each of these levels but disabled parents and their families say this is not always happening. It is the services that everyone can use (eg education and health services) which are often the most important to disabled parents and their families. Accessing support can be difficult and disabled parents and their families want better information and communication with services.
12. Disabled parents want support in their own right as individuals and to have their parenting role recognised. They do not want assumptions made about their capacity to parent. Some disabled parents, particularly those with learning disabilities, have felt under pressure to accept interventions by services which have low expectations about their parenting capacity.
13. Young people providing support to their parents value information and assistance but parents and family members are concerned about councils' expectations that family members will provide significant amounts of support to the disabled parent.
14. Parents and families need information and individual advice about how services can help, particularly for planning ahead in case of a crisis. Different types of support are required at different times to meet changing individual and family circumstances. Disabled parents are finding they are frequently left to cope with fragmented responses to their needs.

Local strategies and policies

15. In our survey, 66% of councils reported that their policies tended to focus separately on adults' and children's issues.
16. Only 17% of councils in our survey had collected any information about disabled parents and their families living in their area so few are planning and commissioning services on a basis of knowledge.

6 Department of Health (2002) Local Authority Circular LAC(2002)13. *Fair access to care services: guidance on eligibility criteria for adult social care*. London: Department of Health.

17. Although local policies claim to be based on a social model of disability, an understanding of its implications is not always evident.
18. National policy on personalisation is seen as a very positive step towards better support to disabled parents and families but most councils are at early stages in developing and implementing local policies.
19. *Think family* is also at an early stage in influencing local strategy towards disabled parents and families. Only 12% of councils in our survey reported that they took a whole-family focus.
20. Resource disputes indicate the lack of joint policies and strategies in many councils. Preventative strategies are also being hampered by a lack of joint policies and resource pressures.

Putting local policies into practice

21. Only 30% of councils had developed any kind of joint protocol to establish a shared understanding of roles and responsibilities within the council and with other partner agencies. This is significant as joint working and delivery between *adults' and children's services* is being challenged by:
 - Different eligibility criteria and disputes about financial responsibilities.
 - Different views on the focus of support and tensions between child protection and supporting people with their parenting role.
 - Fewer informal communications between frontline staff and more dependency on senior management collaboration since the separation of adults' and children's services.
 - The focus on the integration of services for children distracting attention from maintaining links between adults' and children's services.
22. In the absence of joint working protocols, collaboration with other agencies also tends to rely on more informal methods.
23. There are good examples of steps to reach out to disabled parents and families but these are not consistently taken.
24. More assistance is needed to support the implementation of Direct Payments and Individual Budgets and to develop the necessary local services that people can purchase.

Conclusion and recommendations

Disabled parents and their families continue to face difficulties in accessing services which support family life. This includes services that everyone

uses, such as education and health services, as well as social care services. This report shows that councils are failing to achieve the right balance of interventions to support disabled parents and the family. Extra efforts are required to overcome the new silos that have been created by the separation of adults' and children's services so that there is not a disjointed approach to supporting the family. There are a number of actions that need to be taken by councils and other agencies. These include:

- **Joint working and integrated services**

A minority of councils have adopted a well communicated and clear policy that incorporates both *Think parent* and *Think family*, or have agreed joint protocols between adults' and children's services and with other agencies to ensure clarity about responsibilities and a coordinated approach to providing support. There is an urgency for councils to work on agreeing joint protocols as one way of addressing the organisational and cultural differences evident in this report and to ensure no child or disabled parent 'falls through the gap' in services.

- **Better information for joint strategic needs assessments**

Joint planning and the development of an appropriate range of local services need to be based on better understanding and knowledge of the current and emerging needs of disabled parents and their families, which should inform joint strategic needs assessments.

- **More Direct Payments and Individual Budgets**

Direct Payments and Individual Budgets are seen as an important way to ensure more flexible support to families. Advocacy and brokerage schemes should be available to support the use of these. The potential of personal budgets for the whole family should be explored.

- **Resourcing support to the family**

In the absence of publicly funded support or alternative open-access services that can offer assistance, there continues to be an over-reliance by councils (and others) on members of the family, often children, to provide the assistance needed. There appears to be little overt questioning of a strong focus in some areas on services to support 'young carers' but no equal attention to supporting disabled parents. It will be important, first, to monitor how far local councils, in their role to ensure their areas are good places to live, are developing services and support to all local families, including disabled parents; secondly, to assess how far they are achieving the right balance between supporting disabled parents and supporting 'young carers'.

- **Ongoing support and training for staff**

Councils and their partner organisations will need to ensure their staff are skilled and supported in undertaking assessments and working alongside disabled parents and their families to fully understand the needs of parents, those of the children, and the interrelated needs of the whole family. Practice in making decisions about eligibility for publicly funded support should also be monitored to ensure proper adherence to the Fair Access to Care Services guidance.

- **Involvement of disabled parents and their families**

Given the variety of situations, the range of potential needs of disabled parents and the sometimes conflicting needs of family members, there are challenges to coordinating assessments and services to ensure personalised support to disabled parents and their families and to address the current fragmented support system. However, councils need to ensure they are meeting the human rights of everyone to respect for private and family life and equality of opportunity for disabled people. The current difficulties experienced by disabled parents and their families and the lack of opportunities compared to other parents and families indicate there is still much more to be done at policy, operational and practice levels.

Involving disabled parents in developing and monitoring local protocols and support services will be an important step towards ensuring services are accessible and non-stigmatising. Their involvement will also help to encourage action by all the other agencies and services, such as health, housing and transport, that need to be fully engaged in making local communities accessible and inclusive for disabled parents and their families.

Introduction

This introductory chapter sets out the reasons for the Commission for Social Care Inspection's (CSCI's) study, the background to the topic, methods and study partners.

The **key points** in this chapter are:

- Policy and research have often taken a 'fragmented' approach to the needs of disabled parents and their families. The focus in this report is on understanding how far councils are providing holistic and appropriate support to disabled parents and their families.
- Existing evidence raises concerns about the extent to which disabled parents' needs have been identified and responded to, particularly in light of the separation of adults' and children's services.
- Evidence-based guidelines developed by the Social Care Institute for Excellence (SCIE) provide councils with a structured framework for developing strategies and delivering appropriate support to disabled parents and their families and a benchmark for good practice, which this report uses to assess progress.
- This CSCI report has been aligned closely with work currently being undertaken by the Office for Standards in Education, Children's Services and Skills (Ofsted) on young people providing support to their parents.

1.1 Support for disabled parents and their families

"...the problems we face are because there is a perceived contradiction between being a parent and being disabled, as if you can't actually be both." (Disabled mother)

"I'm disabled, I'm a parent – but never the twain shall meet. The two services argue and I'm left in the middle." (Disabled mother)

Over the past decade, there has been increased recognition that many disabled adults have parenting responsibilities. The ways services for adults and families are designed, accessed and delivered should ensure that the parenting role is fully supported. Health, education, housing, adult social care and children's and families' services are all important potential sources of support. Often, if help is provided to the disabled parent to undertake their parenting role, no additional assistance is needed for the family.

In 2006, SCIE⁷ undertook a comprehensive review of existing research and the literature in this area which showed:

- There are significant gaps within the current policy framework where parenting roles are not treated as a central issue and requirements for inter-agency work have tended to focus on safeguarding children rather than supporting parents.
- Current structures and procedures present barriers that mean the response to the needs of families where one or both parents are disabled or who have additional support needs is crisis-driven and short term.

*Every child matters*⁸ and the subsequent Children Act 2004 led to the integration of children's social care and education and the separation of children's and adults' social care services. The separation created new organisational boundaries which need to be addressed if coherent and integrated approaches to support disabled parents and their families are to be developed.

In 2007 SCIE produced a resource guide, *Working together to support disabled parents*, to help address these issues and to develop inter-agency protocols that support parents and families⁹. The guide provides a useful benchmark for evaluating progress in the sector. The principles and key features of good practice are provided in Appendix 1.

This CSCI report seeks to examine the experiences of disabled parents and their families and to see how far council policies, services and practice are providing appropriate support.

This report is based on the social model of disability which focuses on the

7 Social Care Institute for Excellence (2006) *Supporting disabled parents and parents with additional support needs*. London: Social Care Institute for Excellence.

8 Department for Education and Skills (2004) *Every child matters: change for children*. London: Department for Education and Skills.

9 Social Care Institute for Excellence (2007) *Working together to support disabled parents*. London: Social Care Institute for Excellence.

barriers that disabled individuals experience, including attitudes towards disabled people, rather than focusing solely on people's impairments. Proponents of the social model of disability do not deny that medical interventions may assist some disabled people, particularly emphasising choice and control in health services and reduction of pain or level of impairment as positive outcomes. The difficulty with the medical model of disability is that the focus is on cure or segregation, rather than equality, as the solution to the difficulties that disabled people experience¹⁰. The social model underpins current government strategy on improving the life chances of disabled people and the public sector legal duty to promote disability equality¹¹. It is also the approach taken by the Disabled Parents Network (DPN)¹².

1.2 Defining disabled parents

In this report 'disabled parents' include:

- parents who have physical and/or sensory impairments
- parents with learning disabilities
- parents with mental health problems
- parents with drug- and alcohol-related problems
- parents with long-term medical conditions, such as living with HIV
- parents who identify as part of the Deaf community.

It is also important to recognise that some parents with additional support needs relating to impairment may not identify as 'disabled parents'. Thus disabled parents are a very diverse group of people in relation to gender, ethnicity, religion, socio-economic status, sexual orientation and impairments.

SCIE estimates that about 12% of Britain's 14.1 million parents are disabled and 1.1 million households with dependent children have at least one disabled parent. As well as this, a large number of parents have additional support needs¹³.

10 Commission for Social Care Inspection (2009) *Putting people first: Equality and Diversity Matters 3. Achieving disability equality in social care services*. London: Commission for Social Care Inspection.

11 Prime Minister's Strategy Unit (2005) *Improving the life chances of disabled people. Final Report*. London: Prime Minister's Strategy Unit.

12 Disabled Parents Network (www.disabledparentsnetwork.org.uk).

13 Social Care Institute for Excellence (2006) *Supporting disabled parents and parents with additional support needs*. London: Social Care Institute for Excellence.

1.3 Building good practice: messages from research

For some time, studies have highlighted shortfalls in services to disabled parents, and problems in the coordination of services for children and adults to ensure parents are appropriately supported^{14, 15, 16, 17, 18}.

In 2000, the Social Services Inspectorate¹⁹ highlighted the importance of local policy and protocols to ensure disabled adults' needs are met, including in relation to parenting responsibilities. In 2006, CSCI focused specifically on the experiences of families where the children were on the child protection register²⁰. Whilst the focus of that study was not on families which include disabled parents, the findings have clear relevance to this current report: support requirements of parents were not always recognised, and there was a failure to collect information about disabled parents to support service planning. Access to support was often restricted by eligibility thresholds and resource limitations, which could mean needs were not recognised or were met too late.

The tendency within policy and practice to 'fragment' families in terms of 'cared for' and 'carer' relationships has reflected the ways in which services have been organised and delivered. This approach has not properly recognised disabled parents' needs in their own right, nor facilitated an understanding of interdependence within families.

Since the mid-1990s, research has focused on the experiences of disabled parents and their families. Prior to this, disabled parents were often invisible within both parenting and social care and social policy literature. This in part

- 14 Wates M (1997) *Disabled parents: dispelling the myths*. London: National Childbirth Trust/Radcliffe Medical Press.
- 15 Social Services Inspectorate (2000) *A jigsaw of services. Inspection of services to support disabled adults in their parenting role*. London: Department of Health.
- 16 Olsen R and Tyers H (2004) *Think parent: supporting disabled adults as parents*. London: National Family and Parenting Institute.
- 17 Commission for Social Care Inspection (2006) *Supporting parents, safeguarding children. Meeting the needs of parents with children on the child protection register*. London: Commission for Social Care Inspection.
- 18 Mencap (2008) *Providing the right support for parents with a learning disability*. London: Mencap.
- 19 Social Services Inspectorate (2000) *A jigsaw of services. Inspection of services to support disabled adults in their parenting role*. London: Department of Health.
- 20 Commission for Social Care Inspection (2006) *Supporting parents, safeguarding children. Meeting the needs of parents with children on the child protection register*. London: Commission for Social Care Inspection.

reflects a failure to acknowledge disabled people as providers of care (including parenting). Where parents were visible, the focus was often on ‘problems’ or ‘deficits’, rather than barriers and equal opportunities to parenting.

Disabled parents themselves have challenged their invisibility and highlighted their experiences in negotiating access to appropriate services, particularly where there is a fear of stigmatisation and inappropriate intervention in family life:

“...the association is easily made between being seen as different and being seen as problematic. And so, from a disabled parent’s point of view, doing one’s best to appear normal may seem like the safest route to a family life free from unwelcome intervention²¹.”

Research funded by the Department of Health²² involving over 70 disabled parents and their families confirmed that the forms of support that disabled people most often value in parenting their children are intrinsically no different from the kind of support that all parents need. These include an adequate income and appropriate housing, being able to take an active part in their children’s education, and being able to access services and facilities within the community such as health services and leisure and voluntary organisations.

Not equating ‘disabled parent’ with ‘child in need’, ‘thinking parent’ and recognising that disabled parents can face barriers in accessing services and support (including mainstream services) are key to the development of good practice.

Other research concerning the experience of children who have a caring role within the home²³, and more generic work concerning ‘carers’ (including partners who are carers^{24, 25}), has highlighted some of the implications

- 21 Wates M (1997) *Disabled parents: dispelling the myths*. London: National Childbirth Trust/ Radcliffe Medical Press.
- 22 Olsen R and Clarke H (2003) *Parenting and disability: disabled parents’ experiences of raising children*. Bristol: Policy Press.
- 23 Dearden C and Becker S (2004) *Young carers in the UK. The 2004 Report*. London: Carers UK and the Children’s Society.
- 24 Parker GM and Seymour J (1998) ‘Male carers in marriage: re-examining feminist analysis of community care’, in Popay J, Hearn J and Edwards J (eds) *Men, gender divisions and welfare*, pp 181–194. London: Routledge.
- 25 Parker G (1993) *With this body: caring and disability in marriage*. Buckingham: Open University Press..

for parents, their partners and families where disabled people's support requirements are not met.

1.4 About this report

This report explores the extent to which councils have developed and implemented strategies for disabled parents and their families which are in line with current government policy, including human rights and disability equality legislation, and based on the lessons learnt from research and the recent SCIE guidance. In particular, the report examines:

- Whether there is appropriate support for disabled parents in fulfilling their parenting responsibilities.
- The formal arrangements and monitoring systems in place between adults' and children's services to ensure the needs of families are addressed as a whole.
- The ways councils and their partner agencies are planning to ensure their localities and services are accessible and inclusive for disabled parents and their families.

To address these issues the study undertook a national survey of 50 councils with lead senior managers, or joint leads where in post. Of the 70 interviews, 36 were conducted with representatives of adults' services and 32 from children's services, and two were conducted with a representative from each service jointly. Interviews examined council perspectives on delivering support to disabled parents, service development and delivery, inter-agency working and good practice.

To supplement the national picture, in-depth study workshops of services were conducted in four council areas. These reviewed support provided to disabled parents by councils and their health, voluntary sector and other partner agencies. Disabled parents and their families, including children, contributed to these workshops alongside representatives from councils and their partner organisations, health and other services. The workshops identified key local issues, the rationale behind service provision, and disabled parents' and family members' experiences of services and access to them. Good practice was identified in the course of the workshops.

1.5 Project partners

As part of this study, CSCI consulted with the Audit Commission, Healthcare Commission, Ofsted, SCIE and Disabled Parents Network.

CSCI has liaised with Ofsted who conducted a survey to assess the progress

eight councils have made in identifying and assessing the needs of young people providing support to their parents. The findings from Ofsted's survey will be published in 2009.

CSCI's four in-depth study workshops are being followed up by practice development days facilitated by SCIE. This work will help councils and their partners to develop and improve arrangements for the delivery of services to disabled parents and their families. SCIE will publish the proceedings of the practice development work in 2009.

1.5 Structure of this report

National policies and initiatives relevant to support for disabled parents and their families are discussed in chapter 2. Chapter 3 summarises what disabled parents want and their experiences of services. Chapter 4 examines the local strategies and policies councils and their partners have in place. Chapter 5 looks at how these policies have been implemented and the delivery of services and support. Key issues and actions are summarised in the concluding chapter.

Throughout this report we draw on quotations from the interviews and group workshops. During the workshops key principles for support were agreed between disabled parents and their families, council staff and their partner agencies and these principles are presented in boxed text.

Policy context

This chapter identifies current policies and guidance relevant to support for disabled parents and their families.

The **key points** in this chapter are:

- Councils have responsibilities under current policy both to support disabled parents who have children and to support children who assist their disabled parents. This was policy before the separation of adults' and children's services, but since then competition between departments as to who 'owns' the issues of the family has escalated. As a consequence, families can feel in a situation where they are out of control.
- However, recent policy developments offer opportunities to address these problems. These include:
 - the *Putting people first* concordat, which emphasises support²⁶ to maximise the ways people can direct their own support
 - *Think family*, where the importance of inter-agency working, including between adults' and children's services, is the key to adopting a family approach^{27, 28}.
- The Human Rights Act 1998, upholding the right to respect for private and family life, and the Disability Discrimination Act 2005, prohibiting some discrimination against disabled people in the provision of services, should underpin work to support disabled parents.
- The Fair Access to Care Services²⁹ guidance reinforces the importance of supporting people in their parenting roles.

26 Her Majesty's Government Ministerial Concordat (2007) *Putting people first: A shared vision and commitment to the transformation of adult social care*. London: Department of Health.

27 Cabinet Office Social Exclusion Task Force (2007) *Reaching out: think family*. London: Cabinet Office.

28 Cabinet Office (2008) *Think family: improving the life chances of families at risk*. London: Cabinet Office.

29 Department of Health (2002) Local Authority Circular LAC(2002)13. *Fair access to care services: guidance on eligibility criteria for adult social care*. London: Department of Health.

Councils have responsibilities to meet policy on supporting disabled parents and on supporting children who look after disabled parents. This was policy before the separation of adults' and children's departments, but with the separation there has been an element of competition introduced as to who 'owns' family issues. Support to disabled parents and their families has tended to fall between different services and organisations, although policy and guidance have identified some of the cross-cutting issues. More recently, policy emphasis on individual control and control over care and support, on the needs of the whole family, and on human rights and equal opportunities, have offered important opportunities to address the 'gap' between services through which disabled parents and their families can fall.

2.1 Putting people first

Putting people first (a joint protocol between central and local government, the care sector's professional leadership, providers and CSCI) underlines the importance of maximising people's control over the services they use³⁰. The focus is on enabling people who use services to shape their own support (personalisation) and an increased commitment to early intervention to maintain people's independence and quality of life. Part of the approach includes the development of individual and personal budgets and Direct Payments to maximise the ways individuals direct their support.

Putting people first aims to ensure that everyone, irrespective of illness, impairment or disability, is supported to:

- live independently
- stay healthy and recover quickly from illness
- exercise maximum control over their own life and where appropriate the lives of their family members
- sustain a family unit which avoids children being required to take on inappropriate caring roles
- participate as active and equal citizens, both economically and socially
- have the best possible quality of life, irrespective of illness or disability
- retain maximum dignity and respect.

2.2 Children's services and disabled parents

Local councils' responsibilities to promote and improve the well-being of children are set out in *Every child matters*³¹. Councils are expected to consider

30 Her Majesty's Government Ministerial Concordat (2007). *Putting people first: a shared vision and commitment to the transformation of adult social care*. London: Department of Health.

31 Department for Education and Skills (2004) *Every child matters: change for children*. London: Department for Education and Skills.

whether an assessment under the *Framework for the assessment of children in need and their families*³² is appropriate when they have identified children with needs in their own right and/or needs which directly relate to the parent's experience of disability and impairment (or chronic health difficulty). The guidance emphasises that “the provision of services that assist disabled parents who need support in bringing up their children is often the most effective means of promoting the welfare of the children”.

2.3 **Think family: bridging gaps in social care**

A recent review of families at risk of social exclusion, conducted by the Cabinet Office³³, highlighted the need to think about families holistically and emphasised that whilst individual family members may have support needs in their own right, people within families often have interrelated needs which can increase the extent of exclusion faced, particularly in the ways services are organised. This can result in a fragmented understanding of the problems faced by families.

The review focused on the needs of those families considered most at risk of social exclusion, facing multiple problems, such as poverty, unemployment, and health problems or impairment. The interrelated nature of these issues is recognised, as is the importance of understanding individual needs in the context of their family relationships and roles. Inter-agency working and coordination between adults' and children's services are highlighted as key to ensuring that services adopt a 'think family' approach. Government has launched a series of family pathfinder projects to explore the best ways to put this into practice³⁴.

In 2009, government launched a new three-year strategy for people with learning disabilities which emphasised their right to become parents and the need for adequate support to sustain the family unit³⁵.

32 Department of Health, Department for Education and Employment and Home Office (2000) *Framework for the assessment of children in need and their families*. London: Stationery Office.

33 Cabinet Office Social Exclusion Task Force (2007) *Reaching out: think family*. London: Cabinet Office.

34 Cabinet Office (2008) *Think family: improving the life chances of families at risk*. London: Cabinet Office.

35 Department of Health (2009) *Valuing people now: a new three year strategy for people with learning disabilities*. London: Department of Health.

2.4 Human rights and disability equality

The Human Rights Act 1998 and the principles of fairness, respect, equality, dignity and autonomy apply to everybody. The right to respect for family and private life and prohibition from discrimination is highly relevant to disabled parents and their families³⁶.

Disability equality law has two important facets for disabled parents. The first legislation protecting disabled people against discrimination in services was the Disability Discrimination Act 1995. More recently the Disability Discrimination Act 2005 places a general duty on all public sector authorities to promote disability equality. Social care services procured by public sector authorities must ensure the needs of disabled people are met and due weight should be given to the requirement to demonstrate a good understanding of the social model of disability in social care³⁷. It is important not to see human rights and disability equality as separate agendas, as they are inextricably linked – partly because equality is one of the principles of human rights legislation, but the other principles are also highly relevant to equality for disabled people³⁸.

2.5 Access to publicly funded social care

Fair Access to Care Services (FACS)³⁹ is a trigger for intervention by public services. It provides an eligibility framework, graded into four bands (critical, substantial, moderate and low), which describe a range of risks to independence and well-being if social care needs are not addressed. Councils themselves can decide how many bands to make available in their area. People who are deemed eligible for social care services are then financially assessed to determine how much they have to contribute to their care. Family roles and responsibilities are included in the framework with critical risks to independence to be given equal weight, including in relation to parenting. For example, a critical or substantial risk to maintaining parenting roles is therefore of the same importance as a risk to being able to carry out personal

36 British Institute of Human Rights (2006) *Your human rights: a guide for disabled people*. London: British Institute of Human Rights.

37 Disability Rights Commission (2006) *The social care sector and the disability equality duty: a guide to the disability equality duty and Disability Discrimination Act 2005 for social care organisations*. Stratford Upon Avon: Disability Rights Commission.

38 Commission for Social Care Inspection (2009) *Putting people first: Equality and Diversity Matters 3. Achieving disability equality in social care services*. London: Commission for Social Care Inspection.

39 Department of Health (2002) Local Authority Circular LAC(2002)13. *Fair access to care services: guidance on eligibility criteria for adult social care*. London: Department of Health.

care. Guidance stresses that disabled parents' requirements may often be best met through appropriate adult assessment and also emphasises the importance of joint policies and protocols between adults' and children's and families' services⁴⁰. However a recent review by CSCI of the FACS guidance on eligibility and its implementation has shown considerable differences in how this framework for eligibility has been interpreted in practice⁴¹.

2.6 Summary

The policy, legislation and guidance within which adults' and children's services operate are summarised by SCIE⁴² in the following box.

- “Local authorities and all other agencies working or in contact with children have a responsibility to safeguard and promote children's welfare.
- Children's needs are usually best met by supporting their parents to look after them.
- Professionals should respect and support the private and family lives of parents who have additional support needs associated with physical and/or sensory impairment, learning disabilities, mental health problems, long-term illness, and/or drug and alcohol problems.
- Disabled parents and those who appear to be in need of community care services have the right to an assessment of their needs and have the right to have their assessed needs met if they meet local eligibility thresholds. Assessments should gauge any assistance required with parenting roles and tasks.
- When determining eligibility for adults' services, social services should take into account any risks in the short and long term which may affect the capacity of a parent to carry out family roles and responsibilities.
- Decisions as to whether to provide support should also take into account the consequences of not meeting needs which fall outside eligibility thresholds.
- Adults' and children's services – across health, education and social care – should work together to improve outcomes for children and their families.
- Disabled parents are entitled to the same access to services as all parents, including parenting support and information services.
- All public bodies have a duty to actively promote equality of opportunity for disabled people.
- The NHS and local authorities have a duty to promote the health and well-being of their local populations.”

41 Commission for Social Care Inspection (2008) *Cutting the cake fairly: CSCI review of eligibility criteria for social care*. London: Commission for Social Care Inspection.

42 Social Care Institute for Excellence (2007) *Working together to support disabled parents*. Adults' services resource guide 9. London: Social Care Institute for Excellence.

Disabled parents' and families' experiences and views

This chapter considers disabled parents' and their families' day-to-day experiences and their views on support for individuals and family life.

The **key points** in this chapter are:

- Parents are part of families and families are part of communities; support should be provided at each of these levels but disabled parents and their families say this is not always happening.
- Accessing support can be difficult and disabled parents and their families want better information and communication.
- Disabled parents are finding they are frequently left to cope with fragmented responses to their needs.
- Disabled parents want support in their own right as individuals and to have their parenting role recognised. They do not want assumptions made about their capacity to parent. Some disabled parents, particularly those with learning disabilities, have felt under pressure to accept interventions by services which have low expectations about their parenting capacity.
- Young people providing support to their parents value information and support.
- Parents and family members are concerned about councils' expectations that family members will provide significant amounts of support to the disabled parent.
- Parents and families need information and individual advice about how services can help, particularly for planning ahead in case of a crisis.
- Different types of support are required at different times to meet changing individual and family circumstances.
- It is the services that everyone can use (eg education and health services) which are often the most important to disabled parents and their families.

3.1 Understanding us and our families

Disabled parents and their families receive good support when:

“...we feel part of the community and feel accepted.”

“...when life is more planned, when support gives us back our lives to do the things we want to do without fretting.”

Parents want an opportunity to engage as a person in their own right in all aspects of society, whether that be through involvement in their own health and social care decisions, or more widely in leisure, employment and education.

“A lot of the problems we face are because there is a perceived contradiction between being a parent and being disabled, as if you can’t actually be both. Parks can be inaccessible – many are to me and I’m a wheelchair user. Physical access to playgrounds and schools is variable. It’s the perceived contradiction between being a disabled person and being a parent. It’s even shown up by how disabled loos don’t have condom machines – as though disabled people won’t have sex!”
(Disabled mother)

The challenge for services is to ensure their work is based on an understanding of the range of issues disabled parents and their families face. Disabled parents’ testimonies about their lives highlight the importance of public services and spaces, and home and neighbourhood, in shaping their experiences of parenting and family life. Opportunities for family members to have time together, and separately, were considered vital. Socialising, either as a family or with friends, was seen to be important but a lack of support could make planning social lives difficult.

3.2 Getting help

Disabled parents and their families receive good support when:

“...fully aware of rights and know how to operate them.”

“...there is clear accessible information, and good customer care and communication.”

Disabled parents and their families said that a lack of information was often the most important stumbling block when trying to access services ‘from the outside’. This could result in some families not receiving services, despite their entitlements:

“I’m a dad with mental health difficulties and my wife has a physical impairment. Me and my wife support each other, and our kids have turned out wonderful. We haven’t had the help we should have had and with mental illness you are not always in the position to fight for things, and not feel able to communicate.” (Disabled father)”

The lack of information and clear communication from councils and other services was repeatedly raised:

“Families might not know what services are out there – finding the right person or people to talk to is often the first hurdle.” (Disabled parent)

Parents and their families told us that they did not always know where to go. There is no obvious *“department dedicated to disabled parents within the council – so you don’t know where to go and go round and round.”* Parents want *“ease of access”* and *“when you pick up the phone directory it needs to be obvious where to go”*. They also wanted responsive services. Parents are frequently forced to leave messages on answer machines when they did not have a named person to contact. Some people emphasised the importance of having *“a real person on the end of the phone and not an answer machine that you don’t get a reply from.”*

Information packs about services with clear named contacts were also seen to be important. Specific issues were raised by Deaf parents and parents with learning disabilities about deficiencies in information provided and the need for British Sign Language translation of materials, and Easy Read formats. Parents also described technological solutions which could improve access to information and services, such as video-phone interpreting and use of mobile phones for parents to store key contacts and their numbers.

3.3 Support in our own right

Disabled parents and their families receive good support when:

“...people are at the centre... when quality of life has improved and there is increased independence.”

Disabled parents find it difficult to access services in their own right. This may be due to a lack of information about what could be available, because they did not meet the local criteria for adult social care services, or because services which were available did not always take into account their role as a mother or a father:

“We want a bit more help, not to hear that your kids should get on with it and do it for you – when you haven’t had the support you should have.”
[Disabled father]

“We would like a carer who is a qualified child carer as well so I don’t get told, ‘can’t touch your child’.” [Disabled parent]

Many people expressed their concerns that services often saw non-disabled family members as ‘carers’, and this could impact on family life:

“There are problems where there are expectations on other family members and services are taking them for granted.” [Disabled parent]

For some parents, councils’ expectations of their children were not always reflected in the way in which they were involved in meetings with professionals. Parents did not want children to be relied upon (for example as an interpreter), but sometimes felt that the type of involvement individuals or families had with professionals was not negotiated, or that the reasons for inclusion or exclusion of family members was not clear. For example, some young people providing support to their parents spoke of not being listened to when a social worker called, and found this frustrating given the level of support they felt professionals expected of them.

3.4 Experiences of uncoordinated services

Disabled parents and their families receive good support when:

“...professionals communicate well with each other so I don’t have to do it all myself and feel like no one is listening.”

Another important aspect of communication commonly expressed by family members receiving services was the need for professionals to share information about a family so that they did not need to repeatedly tell their stories or discuss their circumstances with different professionals.

“It can be stressful dealing with lots of different people from different services.” [Disabled parent]

Families want *everyone* involved to share information and understand their needs so that everyone is able to work towards shared goals.

“...when there is not a single dialogue with the service user it is a problem.” [Disabled parent]

Some people wanted a ‘link worker’ between the family and the various services involved to help coordinate services.

“We think it would be important to have a link worker to play the coordinating role rather than having to speak to lots of people and repeat the same thing over and over again.” [Disabled parent]

This named link worker would mean family members know who to ask if they want to get help, and would allow them to form a trusting relationship with someone who knows them well and understands their situation.

3.5 Thinking about the whole family

Disabled parents and their families receive good support when:

“...there is the right level of support for a disabled parent and recognition that different members of the family have different needs: more support for parents would mean less support needs for young people themselves.”

Supporting one another in families is fundamental to people's lives. Some parents know that young people can find it difficult to talk to peers at school about their parent's impairment and their caring role. The benefits of being able to share experiences with other young people in similar positions in a supportive and safe environment was highly regarded.

Some parents felt children could receive more support but there were also concerns expressed that inappropriate levels of care were being expected:

“Young people should be enjoying their lives and not having to look after their parents.” (Disabled parent)

One parent, for example, felt that councils' expectations of her daughter to be involved in 'housework' went far beyond this due to a lack of formal carer support when her husband was working nights:

“The care manager said my 9 and 15 year olds could do housework like making beds and washing up. But in practice my daughter ended up doing my care to put me to bed with the hoist, to empty my catheter. My daughter was doing her GCSEs and I was absolutely devastated and that situation hasn't been addressed.” (Disabled mother)

Deaf parents also identified expectations that their hearing child would interpret or support communication on particular issues. One Deaf father with a young infant son said he was worried about expectations (especially in relation to interpretation) which might be placed on his child in the future:

“I don’t want to rely on my son in the future, I don’t want to be put in this position.” (Disabled father)

Disabled parents and their families receive good support when:

“...everyone is listened to and there is no pre-judging by professionals.”

Disabled parents are concerned that professionals “*can arrive thinking something’s going on and be wrong*” and can have low expectations about parenting capacity, particularly of people with learning disabilities. Assumptions are made that their family has a particular problem or a problem is more serious than the family perceives it to be. It is “*important for parents to be listened to*” if assessments are to be accurate, and the priorities of the family understood and responded to.

Parents also find that assessments can be service-led, guided by the services known to be available and the criteria for accessing them, rather than by the needs of the family. Parents described this as “*fitting people into services*”, rather than developing services to meet identified need.

Families can be fearful of the response of social services and this can prevent them from seeking the help and support that they need, in particular fearing that their parenting capacity and the safety of their child will be examined and their children might be “*taken away*”. There was also fear that “*once I’m known to social services, they will know me forever*.” Parents were worried about losing control over family life to “*interfering*” services.

3.6 Support in a crisis

Disabled parents and their families receive good support when:

“...everyone is listened to and there is no pre-judging by professionals.”

Help in a crisis was a significant theme within workshops, in contrast to the majority of interviews conducted with lead professionals who focused on longer-term prevention work. Parents and their families were also concerned

that a lack of information could mean that they only found out about services once a crisis point had been reached and would prefer information and advice to be able to plan ahead in case of a crisis. A young person noted:

“You don’t get help until crisis point, even when you know in advance that your parent isn’t well.” (Young person providing support to their parents)

Crises can arise if a parent had to be admitted to hospital in both single parent and two-parent households.

“My husband’s health has been bad and he had to get himself to hospital which was scary. He’s my carer and if anything happens to him I don’t know what will happen to me.” (Disabled mother)

This emphasises the importance of understanding the ‘whole family’ in developing appropriate support for the different roles of each member.

3.7 Support over time

Disabled parents and their families receive good support when:

“...there is flexibility, as you need to understand that requirements will change – things don’t stay the same.”

Workshops provided an opportunity for families and people working in services to identify the ways in which services can support people, from before becoming a parent, through different stages in families’ lives.

Whether the early experience of support is for disabled people becoming parents, or for disabled parents when they first acquire an impairment or become ill, people stressed that early relationships with services can have a lasting impact:

“How parents experience services early on can really affect how they feel about both services and...themselves as mums or dads.” (Disabled parent)

Where parents had felt they waited a long time to receive services, they spoke of the ways in which what might seem like small things could have a major impact on themselves and their families:

“Things become a constant struggle. If you wait for instance for months for assessments and adaptations you might struggle to have a bath or a shower and this impacts on how you feel about yourself.” (Disabled parent)

As well as practical support, and the need for a timely response, family members identified that there could be times when emotional support would also be important:

“Families can need and want emotional support if they are experiencing changes, for example if a parent becomes disabled.” (Disabled parent)

Parents and families clearly need different support at different times, often from services which are available to all the community, including health services and education services.

3.8 Equal opportunities to parenting: services for all

Disabled parents and their families receive good support when:
“...all services are truly accessible!”

Families emphasised the importance of a wide range of services which many families, whether or not there is a disabled parent, find useful.

Education

A good relationship with a child’s school is important to parents. They want to be able to reach the school – physically or by letter or phone – to be able to keep in touch about their child’s progress, to let them know about family issues, and sometimes to deal with matters of safety (such as responding to bullying).

Relationships with schools can feel compromised when parents find accessing schools and teachers difficult. Parents feel that schools should not judge parents who cannot get to parents' evenings and that schools should ensure that parents can speak to teachers. Getting to cultural events was also seen to be important but not all schools were accessible. For Deaf parents there could be difficulties in communication where materials were not presented appropriately and interpreters were not provided:

"It is their responsibility to book interpreters – my mum gave the school every number for interpreters, she had done her bit. My mum can feel like she's not worth anything as it makes her feel 'why am I the last person to find out' things from school." (Young person)

The policy of offering a choice of school was not always helpful to disabled parents because of their difficulties in accessing a school close to the family home. Some parents argued that if children were in local schools parents would face fewer problems, such as in getting children to school. Some parents suggested that children of disabled parents should be prioritised in the same way that children in care in the area were in relation to school choice.

In one council, disabled parents and their families were part of the inclusion agenda in primary schools and across the city disabled school governors were to be put in place to raise awareness and support schools to meet inclusion standards. This development was welcomed by parents and family members.

Health services

Good access to health services was considered particularly important, especially GPs, midwives, health visitors and hospitals. Deaf parents identified that visual displays are crucial to ensuring that appointments are reached and for those whose language is British Sign Language, the availability of interpreters was a key issue. Disabled parents did not want to rely on their child or another family member when confidential and sensitive information was being discussed. Disability awareness amongst all front-line staff, including receptionists, was considered important.

Physical access issues were also important, for example having accessible hospital transport. The extent to which health services were child friendly was also important; for example, for parents with mental health difficulties child-friendly visiting/meeting rooms in hospitals were valued.

Parents are concerned that there is no “ownership” of disabled parents’ issues by professionals working in community settings:

“Do health professionals have knowledge about all the services families might be able to access – for example do doctors know about the carers’ centre?” [Disabled parent]

Disabled parents agree that all services need to be more responsive and that there should be a clear route to more specialist support via those services which are often the first point of call for all parents. This is an aspiration but is currently not happening for all parents with support requirements.

3.9 Summary

It is the services that everyone can use which are often the most important to disabled parents. Disabled parents are concerned that no assumptions are made about their parenting capacity and do not want unnecessary interference in their lives. Some disabled parents do require additional social care support in their own right, which recognises and supports their parenting role. Parents will have other roles and relationships which should also be acknowledged. The way in which services communicate what is available to families can determine whether or not people are able to find out about support, and young people as well as parents value information and support. Currently there is concern amongst families that support is not always timely or easy to access and is often fragmented, leaving family members to provide significant amounts of support to a disabled parent. Families look to services to provide clear ways of accessing appropriate and coordinated support.

Disabled parents are looking for:

- **Easier access to support** – with accessible information and good communication about where to go and what is available.
- **Good access to services which everyone uses.**
- **Support in their own right as individuals** and to have their parenting role recognised and no assumptions made about their parenting capacity.
- **Information about what to do in a crisis.**
- **Flexible support that matches their changing circumstances.**
- **Information and support for family members** but no expectation that their children and/or partner will take on a caring role.

Local strategies and policies

This chapter considers how far councils' policies and joint strategies set out to provide the support disabled parents and their families seek.

The **key points** in this chapter are:

- Although local policies claim to be based on a social model of disability, understanding of its implications is not always evident.
- 66% of councils in our survey reported that their policies tended to focus separately on adults' and children's issues.
- Only 17% councils in our survey had collected any information about disabled parents and their families living in their area so few are planning and commissioning services on a basis of knowledge.
- National policy on personalisation is seen as a very positive step towards better support to disabled parents and families but most councils are at early stages in developing local policies.
- *Think family* is also at an early stage in influencing local strategy towards disabled parents and families. Only 12% of councils in our survey reported that they took a whole-family focus.
- Resource disputes indicate the lack of joint policies and strategies in many councils.
- Preventative strategies are also being hampered by a lack of joint policies and resource pressures.

4.1 Policies towards disabled parents

Councils varied in their approach and policies towards disabled parents and their families — 33 out of 50 (66%) reported their policies focused separately on adults and children. Only 6 (12%) claimed they took a whole-family focus — these were largely family pathfinder sites.

The focus of policies in relation to disabled parents and their families	
Category	Number of councils
Child focus	6
Adult focus	4
Whole family focus	6
Adult and child separate	33
No clear policy focus	1
Total	50

A small number of councils questioned the importance of identifying disabled parents as a specific 'group' and instead drew on concepts such as empowerment, citizenship and personalisation. These councils challenged the focus on disabled parents, believing not all people with support needs would consider themselves, or be recognised as, 'disabled'. They felt that enabling people should involve maximising control over all personal and social roles, including parenting. One way this was expressed was as "*seeing disabled people's lives in the round*" [head of adults' social care service]. However, council policies varied as to whether their approach was based on a social or a medical model of disability, ie focused on social barriers or health conditions.

There were different approaches in some areas between impairment-specific teams and other adult services (some of whom were co-located within health services). For example, in one area services relating to physical impairments and learning difficulties adopted a social model of disability, whereas other services (such as mental health) were more impairment focused. There were thus challenges in developing shared strategies across services, each with different, long-established approaches to meeting the needs of disabled adults.

Nonetheless, in some areas steps had been taken to have a common approach based on the social model of disability. In one council, for example, joint training was in place which paid special attention to the social model of disability. The implementation of the disability equality duty and the Disability Discrimination Act 2005 had also provided an impetus towards addressing social barriers faced by disabled people and their families, including promoting independent living and enabling disabled parents to maintain control of their parenting role.

However, a social model of disability set out in policies and protocols may not necessarily be translated into practice, especially when staff do not fully understand the model or where these policies may not relate to every service

in a local area. Assessment processes often did not appear to reflect the social model of disability and adult services assessments often focused on the degree or nature of a parent's impairment, linked to local eligibility criteria.

"...as part of the initial assessment they do include the social factors as well, but the primary [focus] is the impairment." (Strategic manager, children's services)

For parents, their impairment may be the prompt for an assessment to take place which may also lead to assumptions of *"inadequate parenting"*. The nature or extent of impairment can often be the *"cut-off point"* in deciding what services can be delivered, *"even though we are signed up to a social model"*. (Senior manager, children's services)

4.2 Strategic commissioning: learning from and about parents

Disabled parents and their families receive good support when:

"...services listen to the voice of disabled people and act on it."

"...it is recognised that there are different needs... and that one size does not fit all."

Few councils systematically collect data about disabled parents to show, for example, how many live in the area, what services they use or what needs are not being met. Only 17 (34%) councils in our survey had undertaken any work to find out about disabled parents living in their area.

How councils understand the needs of disabled parents and their families	
Category	Number of councils
None	29
Don't know	4
Formal monitoring	6
Collaborative work with disabled parents and/or local groups	6
Collaborative work with young people providing support to their parent and/or local groups	1
Research	6
Total	50

Strategic managers in both children's and adults' services said that disabled parents were not identified as a specific group for monitoring purposes. Whilst adults' services may monitor services used by disabled adults, few record whether these people were parents. For example, one council had conducted a recent survey on the views of 1000 disabled adults, but had not asked people whether they were parents or how their parenting role might be supported. Similarly forums or events aimed at understanding the support requirements and perspectives of parents had been arranged, but with no specific focus on disability. Thus in some areas issues specifically faced by disabled parents are not being identified.

The lack of knowledge about the needs of local disabled parents reflects a lack of engagement with disabled parents' groups or organisations. Councils noted a lack of an organised lobby specifically for disabled parents, and a difficulty in finding "*representatives who will give a voice to the needs of this service user group*" (senior manager, children's services). Where such a group did exist, there were sometimes concerns about the dangers of always consulting the same people and therefore not reflecting the diverse population of disabled parents.

Further problems were reported in understanding and responding to specific populations of disabled parents. In some areas, social care services reported difficulties in engaging with minority ethnic groups, particularly where small numbers made the population hard to identify or to engage through established community groups.

Elsewhere disabled adults with particular impairments were thought to be underrepresented in consultation and development work. For example, one workshop identified a lack of council awareness of support needs for parents with learning difficulties.

The broad and inclusive definition of disability adopted by SCIE and in this report highlights the challenges for commissioners. These are challenges in gathering data about needs, engaging with a diverse group of people and achieving a shared perspective across services.

Some believed that these challenges would be addressed if there was legislation or other mandatory requirements to take action. For example:

“To kick start more joint working government could insist we hold a register on disabled parents (who use services) and not just rely on data concerning children in need.” (Children’s service manager)

“I think we would argue that disabled parents have the same rights as non-disabled parents and given that there is no disabled parents’ legislation we don’t identify disabled parents as such. So we focus on disabled adults rather than disabled parents, but can be inclusive of parents within that. Disabled parents’ legislation would provide greater focus for us all.” (Adults’ service manager)

However some councils had identified methods and techniques that were proving to be effective. These include:

- Involvement of disabled parents in strategic partnership boards and commissioning bodies so as to ensure their perspectives are considered in all decisions.
- Use of existing disabled adult forums and consultations to host specific events in relation to parenting.
- Development of new forums for disabled parents, or user-led groups and associations able to offer mutual support as well as consultation. This includes online forums and communities for those who are unable to regularly attend meetings.
- Establishing links with existing community groups to identify disabled parents from minority ethnic groups to consult with effectively and sensitively.

4.3 Policy on personalisation for parents and families

The majority of councils saw the personalisation agenda as crucial to better support for parents and their families. Whilst recognising some of the challenges, the benefits were repeatedly stressed:

“Personalised care and Individual Budgets are likely to influence how disabled people and families experience services in the future – choice and control increased through this approach to service delivery.” (Service manager, adults’ social care service)

“The personalisation agenda with self-assessment will be a huge cultural change, if we get it right it will be a revolution, enabling people to get on with their lives.” (Manager, young adults’ social care service)

Concerns were, however, raised about the extent to which services will be available locally to meet individual needs. Eight councils in our study were involved in the piloting of Individual Budgets. Of these, three reported that meeting disabled parents' support needs required a 'whole-council' approach, with individuals able to express their own requirements through self-assessment processes:

"This council has been a pilot for personalised budgets, and so we have a developing self-assessment process. Self-defining will start to change the way people determine need and how services are shaped or provided and this will be important in relation to family issues." (Service manager, adults' social care services)

"We have been a pilot on Individual Budgets ...we are mainstreaming, and self-directed support is more around barriers than function ...I would say we are moving from being impairment focused to barriers focused, as the disability equality duty and DDA [Disability Discrimination Act] kick in." (Assistant director, adults' social care services)

4.4 Delivering *Think parent, Think family* support

Disabled parents and their families receive good support when:

"...there is mutual respect between everyone – no one is superior – everyone is equal."

In our study five councils had successfully applied for family pathfinder status as part of the *Think family* agenda. Three councils had told us they had not been successful but reported the application process had helped them to cement *Think family* into strategic approaches. Two councils were looking to develop an overarching framework to support families across children's and adults' services. Another council said they were making progress towards adopting a 'whole-family' approach.

One head of adults' social care service reported the *Think family* agenda was leading to 'open door' children's services where accessible and flexible services are open to everyone and offer support to parents and children. Where councils had sought extended pathfinder status (which cover young carer issues), emphasis was placed on children's services (especially

services to support young people providing support to their parents) to reach family members including disabled parents. However, the origin of family pathfinders meant that in some councils the application had been initiated in children's and family services and may not necessarily lead to joined-up working.

"...the family pathfinder was fed through the DCSF [Department for Children, Schools and Families] but it seems at the top they are not working together – it felt that it had to go through children's services and this could be a trick missed. It just doesn't feel very joined up." (Carers' commissioner)

Others found benefits from *Whole family* thinking through the family pathfinders initiative which has helped both children's and adults' services to take ownership of considering all family members, and no longer to consider that support for disabled parents and their families is "*not to do with me*."

Workshops provided an opportunity for families and people working in services to identify the ways in which services can support people, from before becoming a parent, through different stages in a family's life. Professionals in two of the four workshops felt that people with learning disabilities might not always have support to think about what becoming a parent will mean. There was also concern that people with learning disabilities can be expected to plan about every last practicality of having children, and so the expectations could be tougher than on everyone else. If there is a lack of ongoing support for parents this could mean that there were inappropriate expectations:

"Ongoing support is rare as on most occasions we think that a child of a person with learning difficulties [is] taken into care long before the issue reaches adult services to see how the parent can be supported. A key issue for us is that there is no support - a lack of a positive approach to supporting being a parent." (Group discussion of learning disability practitioners)

The views of these practitioners suggest that appropriate support is not always available for some groups of disabled parents.

4.5 Prioritising resources for disabled parents and families

Councils frequently highlighted resource pressures which limited their abilities to meet families' needs. These funding pressures can lead to conflicting interests between services each seeking to protect its own budget. The danger is that a family might "*fall through the net*" with no service being provided. For example, a commonly reported problem was the provision of transport to take young people to school when a parent is unable to do so. Disputes about who pays can lead to no services being provided or, as was the case in one council, a reliance on a charity to provide transport services. The impact of failing to commit resources could be considerable in families who felt it compromised their relationship with schools.

"I've three children, I'm disabled and my husband is disabled. It would be good if I could phone up and occasionally get help getting my youngest to school. You do feel penalised for not getting your child to school."

[Disabled mother]

"We didn't fit the criteria – but there's a bus for disabled children. I've sold my last house to move to a house right outside the school so I can open the door and ask another parent to walk my daughter to school. But friendship, compassion and unpaid for assistance runs out." [Disabled mother]

In some areas formal agreements have addressed these problems. For example, in one council, a protocol between children's and adults' services facilitates the delivery of joint packages of care with the cost usually "*split 50/50*", and some services, such as home care, paid for through pooled budgets. In another council, regular formal meetings are held between senior managers of services to decide on difficult funding situations.

Elsewhere, funding decisions were based on whether there was a "*child in need*", in which case children's services would fund all services related to parenting. In another council, funding decisions were guided by the service taking the lead with a family:

“You would probably need to look to where the primary worker is to see where the majority of funding would come from.” (Senior manager, adults’ services)

Concerns were raised where there was a reliance on informal arrangements between services for making financial decisions to secure services for people.

4.6 Preventative support for disabled parents

Disabled parents and their families receive good support when:
 “...we receive help when we need it and not when we have reached breaking point.”

The value of early intervention and preventative support was agreed by disabled parents and their families, practitioners and service planners. All believed that responsive and flexible services should enable families to access support when they need it and without delay. Early intervention to prevent critical need was raised as an efficient use of managing resources as well as maximising outcomes for disabled parents and families.

In the survey all 50 councils reported taking preventative approaches. Examples of a range of early intervention services or approaches to working with disabled parents and their families were identified by councils:

- Social care staff signposting disabled parents and family members to other relevant services. This was particularly important when families do not meet criteria for accessing adult social care. In these cases, networks of community and voluntary sector services could be utilised, some of which were funded by councils and their partners, such as advocacy, carers’ support, parents’ groups and befriending services.
- Providing access to generic preventative services, as well as those specific to disabled parents or families. Generic services include family support services, children’s centres, parenting classes and health services. Social care was seen as having an important role in ensuring awareness and accessibility of these services.
- Identifying and supporting young people during transition to adulthood, and therefore prior to decisions about their future and having children.

- Assessing and responding to all family members. Prevention within a whole-family approach can mean addressing the needs of other family members so as to avert potential crises. This can include supporting carers to continue caring and, most importantly, recognising where caring responsibilities are inappropriate.
- Assessing potential requirements that might arise in the future, as well as those in the present, and providing information on how to access support when it is needed.

Thirty councils reported having advocacy arrangements in place for disabled people, although these were not specific to parenting. Councils did not report advocacy to support consultation with disabled parents.

However, a number of challenges were apparent in putting these approaches into practice. Most commonly these barriers related to:

- Eligibility thresholds which mean that social care services are often unable to fund services for families who do not meet their local criteria and a lack of adequate ‘signposting’⁴³.
- A lack of resources for preventative services because of the need to support those with more substantial or critical needs.
- The instability of funding to voluntary and community sector services for those people ineligible for publicly funded social care.

“Here we are lucky as practitioners as we have lots of charities and organisations around but this can change on a yearly basis and it’s an ongoing difficulty keeping up. There is also pressure on the voluntary service – [we are] asking voluntary organisations to do a lot on an empty stomach.” [Social worker]

43 Evidence of poor signposting to other sources of support is provided in Commission for Social Care Inspection (2008) *Cutting the cake fairly: CSCI review of eligibility criteria for social care*. London: Commission for Social Care Inspection.

Putting local policies into practice

Chapter 5 looks at how far policies have been implemented and the delivery of services and support.

The **key points** in this chapter are:

- Only 15 councils had developed any kind of joint protocol to establish a shared understanding of roles and responsibilities within the council and with other partner agencies.
- Joint working and delivery between *adults' and children's services* is being challenged by:
 - different eligibility criteria and disputes about financial responsibilities
 - different views and priorities as to the focus of support, whether on child protection or on supporting people with their parenting role
 - fewer informal communications between frontline staff and more dependency on senior management collaboration since the separation of adults' and children's services
 - the focus on the integration of services for children distracting attention from maintaining links between adults' and children's services.
- In the absence of joint working protocols, collaboration with other agencies also tends to rely on more informal methods.
- Specific steps to reach out to disabled parents and families have been taken but are neither consistent nor comprehensive.
- More assistance is needed to support the implementation of Direct Payments and Individual Budgets and to develop the necessary local services that people can purchase.

5.1 Joint working: developing protocols

“What makes it hard is that we all work in isolation – health and social care, children’s and adults’, what would make it easier?” [Social care commissioner]

A partnership approach to delivering services and support to disabled parents and their families is crucial. The SCIE guidance emphasises *“the process of developing joint protocols provides an opportunity for agencies to establish a shared understanding of their respective roles and responsibilities”*⁴⁴.

Of the 50 councils involved in this study, only 15 (30%) had any form of joint working protocols on supporting disabled parents.

Protocols for disabled parents and their families	
Category	Number of councils
No disabled parents and families protocol	35
Any disabled parents and families protocol.	15
<i>These 15 protocols included:</i>	
• generic protocols	12*
• mental health protocol	1
• learning disabilities protocols	2
• HIV protocol	1
• physical impairment protocols	1

*Including two protocols in development

Councils with protocols for disabled parents were at a more advanced stage in the development of their services. However, it is important to recognise that other councils without protocols were developing some good work around disabled parents and their families. For example, one council was focusing on training and on information provision for staff and another was developing consultation events for young people providing support to their parents.

Three councils were developing overarching universal protocols and had engaged support from the Disabled Parents Network [DPN]. Another council

44 Social Care Institute for Excellence [2007] *Working together to support disabled parents*. London: Social Care Institute for Excellence.

was developing their universal protocol following SCIE guidance with plans to create a special post in the council to implement this.

There were reports that good protocols that are implemented can improve outcomes for disabled parents and their families, for example when accessing services:

“It’s about having a holistic approach, assessing people in the context of the family. The protocol focuses on which service does what, when. The ethos is maintaining parental control whilst safeguarding children. Previously service users could be passed around but the protocol says that whoever takes the call holds the case, until it is formally assigned to the appropriate service.” (Strategic manager, adults’ services)

The ways in which a protocol can support access to services was reiterated within another council where the protocol was well established, and there was a specific post in place to ensure continuing development:

“We have a protocol and policy across children’s and adults’ services. The focus is supporting parents in their own right. We also try to assess the individual needs of family members and the context of the whole family. So we’ve tried to bring down eligibility thresholds where the overall context of the family suggests that support is required.” (Service manager and disabled parents lead)

Effective protocols depend on gaining ownership across the council and by all its partners, but this is not always easy. For example, one council found it difficult to engage mental health and substance misuse services as they were not located within the council. However, even partially implemented protocols appear to have brought benefits:

“Whilst the protocol is not yet fully adopted, as an interim measure we can put up to four hours of Direct Payments which is primarily to stop parents being so exhausted that they can’t have any quality time with their children. This is good practice – we have parents come forward and we see, three months later, that parents feel more in control and happier at home, it makes a difference to quality of life.” (Adults’ service manager, care management)

The development of protocols alone is clearly not enough to improve joint working. Our study found even where protocols were in place, not everyone was aware of the arrangement, especially when protocols were “*specialist*” and relevant only to certain topics, such as safeguarding adults or transition between children’s and adults’ services.

5.2 Joint working: between adults’ and children’s services

Our interviews with senior managers across 50 councils highlighted a diverse range of ways in which adults’ and children’s services work together to provide support to disabled parents and their families. This collaboration occurs at various stages in the provision of support to families, including:

- through agreements/protocols regarding responsibility for provision and funding
- in the initial and ongoing assessment of support requirements within a family
- through coordinated provision
- through the joint management or delivery of particular services.

Whilst our survey suggests an extensive *range* of forms of collaborative working, it also highlights a number of specific areas of difficulty in *effective* collaboration between adults’ and children’s services. The most frequently raised challenges were:

1) *Funding and eligibility of services*

Different eligibility criteria mean one service may engage extensively with a family, whilst no support is provided from the other. This can cause confusion amongst families as to what level of support they should expect from particular services and, in some areas, has led to complaints (for example, that parents have not been supported in their own right for their benefit and that of their children). There is no uniform pattern as to which service is more likely to provide support. Whilst children’s services were more commonly presented as able to offer support where adults’ services cannot, some senior managers in adults’ services reported that children’s services were unable to deliver preventative support because of ‘child in need’ categories.

A number of disputes about financial responsibilities for particular people or services also were highlighted. These included particular services that might variably be seen as supporting either the child or the parent (such as transport to school), and new packages of support for young people near to the age of 18 who would receive children’s services for only a short length of time.

2) Differing philosophies of care

Different philosophies as to what the best outcome might be for different members of the family and parents cause confusion. In some instances this could lead to adults' and children's services working towards different outcomes with a family.

Three councils explained that the eligibility thresholds in each service were very different with children's services set at a low threshold compared with adults' services which had a markedly higher threshold.

"...parenting can be compromised...[with eligibility criteria] at a much lower level than that at which thresholds for adults' service assessments or provision... and this leads to children's services getting involved more readily, but unable to provide specialist support to the parent."
[Children's services manager]

3) Changes since the separation of adults' and children's services

A number of additional challenges to effective collaborative working were highlighted, partly linked to the recent separation of adults' and children's social care services. These include:

- The focus of attention on the integration of services for children has distracted attention from maintaining links between adults' and children's services.
- Difficulties for individual staff to keep up to date with recent changes in the legislative and policy frameworks for both children's and adult's services. Social workers said they were not up to date with developments in other services (eg team around the child and the common assessment framework). Staff can therefore feel uninformed as to what can be offered by other services and there can be a lack of understanding about the intended aims and outcomes of other services.
- The separation of the role of children's and adults' social care is leading to perceptions of a separate skill base and expertise, such that children's services staff "*see it as beyond their skill base to interview adults, and vice versa*" (senior manager, adults' services).
- Separate databases and information systems can make it hard to share information electronically.
- There is now far less informal daily interaction between frontline staff, making it harder to communicate about particular cases or to share information. Work across children's and adults' services is now dependent

on key individuals within the management structures communicating effectively and cascading the information down to all staff.

- Some social workers reported little or no contact with colleagues in other directorates. The distance between departments was demonstrated in their different use of terminology and jargon. For example, terms such as ‘review’, ‘case conference’ and ‘planning meeting’ held different meanings for different services leading to miscommunications.

A combination of these factors is making a ‘whole-family’ approach to service provision for disabled parents and their families even more difficult.

“...we as professionals are struggling in terms of understanding what’s available and how to access it which means that services don’t get put in place quickly.” (Social worker)

“Here there is no ‘family service’. So the perspective of service providers is seeing the individual rather than seeing them as a member of a family.” (Social worker)

5.3 Joint working: between social care and other services

As well as extensive collaboration between adults’ and children’s services there is also joint working with a wide range of services, agencies and organisations to support disabled parents and their families. Collaboration was most commonly discussed in relation to health services, particularly primary care trusts, health visitors, midwives, mental health services, physiotherapy, speech and language therapy, housing, home care services, local voluntary disability agencies and local disabled parents’ organisations.

Other services discussed less frequently included young carers’ groups, leisure services, employment services, local community organisations (particularly those supporting minority ethnic groups), Sure Start and children’s centres.

As in the case of collaboration between children’s and adults’ services, the ways in which services work together varies greatly. In our survey 20 (40%) councils had formal partnership boards with representation from various services. Whilst these partnership boards are not focused on disabled parents as a discrete group, there are generally impairment-specific groups involving representatives from various agencies, as well as carers and people using services. For example, learning disability partnership boards have a specific role to find out about parents with learning disabilities in their area and to

ensure they are being supported. Other forms of formal collaboration include joint strategic planning and commissioning, and working together on specific projects, such as the implementation of the Common Assessment Framework and Direct Payments.

Most council representatives acknowledged the importance of ad hoc, case-by-case arrangements based on close relationships between social workers and services. This was seen as a necessary part of any collaborative working, regardless of any formal structures in place. However, these informal arrangements were also seen as vulnerable when not supported by formal protocols. For example, informal working relationships could break down when key staff leave; and support for individual people or families is more readily disputed where no formally established protocol exists, which can lead to delays in supporting parents and families.

The introduction of the new Common Assessment Framework across children's services was frequently identified by practitioners as having the potential to address a number of the current difficulties in supporting disabled parents and their families. Practitioners (in workshops) and lead professionals (in interviews), particularly those from children's services, were clear that assessments did not always need to be carried out by social care staff, such as care managers and social workers. With the new Common Assessment Framework other professionals can take a lead role, including health visitors, education, youth workers and the voluntary sector. This was seen to have the potential to provide a non-stigmatising, more timely and responsive assessment, as any professional engaged with a family at any early stage can complete the form. A Common Assessment Framework can make it easier to share information across children's and adults' services, and between social care, health and education. It therefore offers the potential for one assessment to be shared between all sectors and services.

The Common Assessment Framework was also seen to provide "*a more holistic assessment*", understanding the family in its broadest sense, including friends and neighbours. In doing so, practitioners argued that it considered the circumstances and support requirements of the various family members, both collectively and as individuals.

In combination these factors underline that there is "*no wrong door*" to accessing support. Where previously the route through which a family first sought help and support could have a marked impact on services received, and therefore on outcomes, the introduction of a common assessment, shared across many relevant agencies in children's services, could ensure more equivalent and equitable treatment.

However, some study participants believed that adult services responding appropriately to an individual parent's support requirements should be the best way to support the parent and their family. Whilst referral to children's services could be seen as a solution, some councils felt that for some parents (for example, parents with learning difficulties and mental health needs) the focus was more likely to be on 'parenting capacity' than on support. A further concern expressed was that children's service staff may not be fully trained in disability awareness.

5.4 Reaching out to disabled parents and families

Council representatives were aware of the potential reluctance amongst disabled parents to contact social care services. Overall 19 (38%) councils took some steps to address this, including:

- Producing clear and accessible information describing the positive support that can be offered by social care services.
- Ensuring professionals who have contact with disabled parents are aware of and able to explain the support that could be available, including GPs, health visitors and the voluntary sector.
- Developing formal routes for referral from 'open door' children's centres, community and voluntary services, and health services. This includes sharing assessments where appropriate, and (where the first contact is with community children's services) the use of the Common Assessment Framework.
- Building relationships with local media to publicise good news stories and encourage a positive portrayal of social care services.
- Ensuring the first contact with social care services is a positive one where social workers explain clearly the broad role of social care services and address any anxieties a parent or family member may have.

Many councils discussed their aspirations for adopting a 'no wrong door' approach to help disabled parents and families. However, few councils had put this into practice.

"We provide a school based service which works with parents through meetings and signposting to make sure they are accessing services. From our perspective we do signpost to Direct Payments and this is coming from a supporting disabled parents' perspective." (Children's service manager)

5.5 Choice and control through Direct Payments and Individual Budgets

Disabled parents and their families receive good support when:

“...I can access support and a break when I need and want it. Direct Payments and Individual Budgets are a way forward.”

Individual Budgets and Direct Payments enable parents to direct their own support. One council describes their approach:

“I set up a system here where if my care managers assess a disabled parent we offer up to four hours a week as a Direct Payment for a disabled parent to use as they find most helpful – usually around heavy domestic tasks and cooking. So for example we have a disabled mother who receives four hours’ funding for tasks associated with parenting, and around 14 hours for her own support... We have given disabled dads a Direct Payment, but this has happened less often, and is based on the assessment.” (Physical and sensory impairment lead, adults’ services)

However, parents felt that they did not have clear information about how personal budgets work.

“It’s an issue for us as parents not knowing what is available. This includes needing information about Direct Payments and employing staff. It would be good to have that kind of information – to know how it can work” (Disabled parent)

“Parents can face problems when they aren’t given clear information. This includes sometimes having contradictory messages about services, such as being told different things about what Direct Payments could be used for.” (Disabled parent)

Personalised budgets are commonly seen as having the potential to change the relationship between professionals and disabled parents which may lessen people’s fears of social services ‘interfering’ in their family life and parenting role.

However, this increased control also brings concerns about the potential pressures it puts on disabled parents who become in effect purchasers and managers as well as users of services. Some councils support people in employing their own personal assistants and fund independent brokerage and advocacy schemes. Some parents however prefer to have statutory services taking responsibility for arrangements.

Parents were also concerned that personal budgets alone will not rectify the limited supply of some popular forms of care. For example, parents faced difficulties with the supply of care when seeking support at certain times of day, such as in the mornings, in getting children to and from school, and at mealtimes.

Many hoped that self-directed support might provide more 'person-centred' solutions to appropriately support disabled parents. However, the potential for an Individual Budget to support and benefit the family as a whole was questioned. It was not clear whether Individual Budgets or Direct Payments can become 'family budgets' – for example, whether adults' and children's services can 'top up' Direct Payments to support children who become young people providing support to their parents; or whether families can 'pool' Direct Payments to meet all of their individual and collective support requirements.

Conclusion

Disabled parents and their families continue to face difficulties in accessing services which support family life. This includes services that everyone uses, such as education and health services, as well as social care services. Disabled parents face barriers on a daily basis which deny them the same opportunities as other parents, whether it is negative attitudes about their parenting capacity or social inclusion barriers.

A minority of councils (12%) taking part in our study have adopted a well communicated and clear policy that incorporates both *Think parent* and *Think family*, or have agreed joint protocols (30%) between adults' and children's services and with other agencies to ensure clarity about responsibilities and a coordinated approach to providing support. There is an urgency to address the organisational and cultural differences evident from this study and for councils to work on agreeing joint protocols to address these problems and to ensure no child or disabled parent 'falls through the gap' in services.

Whilst some councils prefer to take a broad 'citizenship' approach to include disabled people who are parents, only a third of councils reported any work to identify the needs of disabled parents and their families living locally. Any joint planning or development of an appropriate range of local services is thus limited by a lack of knowledge. More information needs to be systematically collected by partner agencies to inform joint strategic needs assessments.

Direct Payments and Individual Budgets are seen as an important way to ensure more flexible support to families and advocacy schemes should be available to support the use of these. It will also be important to explore approaches that maximise the potential of personal budgets available for the whole family. However poor practice in undertaking assessments of the needs of disabled parents and their families and local interpretation of eligibility criteria, as well as the level at which thresholds are set according to local resources, have meant disabled parents do not always qualify for these personal budgets or any other publicly funded support.

In the absence of publicly funded support or alternative open-access services that can offer assistance, there continues to be an overreliance by

councils (and others) on members of the family, often children, to provide the assistance needed. It will be important to monitor how far local councils are developing services and support to all local families, including disabled parents; and whether councils have achieved the right balance between supporting young carers and supporting disabled parents.

Councils will need to ensure their staff are skilled and supported in undertaking assessments and working alongside disabled parents and their families to fully understand the needs of parents, those of the children, and the interrelated needs of the whole family. Practice in making decisions about eligibility for publicly funded support should also be monitored to ensure proper adherence to the Fair Access to Care Services guidance.

Given the diversity of situations, range of potential needs of disabled parents and sometimes conflicting needs of family members, there are challenges to coordinating assessments and services to ensure personalised support to disabled parents and their families. However councils need to ensure they are meeting the human rights of everyone to respect for private and family life and equality of opportunity for disabled people. The current difficulties experienced by disabled parents and their families and lack of opportunities compared to other parents and families indicate there is still much more to be done at policy, operational and practice levels.

Involving disabled parents in developing and monitoring local protocols and support services will be an important step towards ensuring services are accessible and non-stigmatising. Their involvement will also help to encourage all the other agencies and services, such as health, housing and transport, that need to be fully engaged in making local communities accessible and inclusive for disabled parents and their families.

Appendix 1: SCIE guide summary

Principles that underpin the development of good practice:

- Local councils and all other agencies working or in contact with children have a responsibility to safeguard and promote children's welfare.
- Children's needs are usually best met by supporting their parents to look after them.
- Professionals should respect and support the private and family lives of parents who have additional support needs associated with physical and/or sensory impairment, learning disabilities, mental health problems, long-term illness or drug and/or alcohol problems.
- Support needs should be addressed by enabling parents to access universal and community services wherever possible and appropriate.
- Additional support needs should be met by the timely provision of specialist assessments and services.
- Agency responses should be needs-led, aim to support family and private life and prevent unnecessary problems from arising.
- Agency responses should address the needs of parents and children in the context of the whole family and not as individuals in isolation from one another.
- Inappropriate tasks and responsibilities undertaken by a child or young person which adversely affect their emotional, physical, educational or social development should be prevented by providing adequate and appropriate support to the parent(s) and their family.
- Diversity should be valued and fully considered in agency responses.

Key features of good practice

- Needs arising from impairment/illness and/or disabling barriers were addressed before making judgements about parenting capacity.
- There should be clarity about the rights of individuals and the responsibilities of organisations.
- There should be good working relationships between agencies and disciplines.
- Service development and delivery should be characterised by a partnership approach.
- There should be a continuum of prevention⁴⁵.

45 Social Care Institute for Excellence (2007) *Working together to support disabled parents*. London: Social Care Institute for Excellence.

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