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**Report of the Task Force on Supporting
Disabled Adults in their Parenting Role**

Jenny Morris



The **Joseph Rowntree Foundation** has supported this project as part of its programme of research and innovative development projects, which it hopes will be of value to policy makers, practitioners and service users. The facts presented and views expressed in this report are, however, those of the author and not necessarily those of the Foundation.

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Executive summary

A Task Force on Supporting Disabled Adults in their Parenting Role was set up by the Joseph Rowntree Foundation, with support from the Department of Health, the Association of Directors of Social Services (ADSS), the Disabled Parents Network (DPN) and relevant voluntary organisations. This report highlights the issues raised by the Task Force and puts forward recommendations.

Many of the concerns identified by the Task Force are in fact reflected in government priorities, in particular the policy that children's well-being should be promoted, wherever possible, by providing support for parents. Many individual practitioners are responding to the needs of disabled parents in flexible and supportive ways. Nevertheless, the Task Force identified that people with physical impairments, sensory impairments, learning difficulties, mental health difficulties, long-term illness or HIV/AIDS experience common barriers to receiving appropriate support in their parenting role. The report highlights that:

- policies and services concerning adults and/or children are commonly developed without consulting or involving disabled parents
- disabled parents often find it difficult to access information and advice, advocacy and peer support
- there are particular problems with the inter-relationship between children's services and adult community care services, and work is required at both national and local levels to create the framework for more appropriate service responses
- while *Valuing People*, the learning disability strategy, identified that more needs to be done to support parents with learning difficulties, this has not so far been addressed in the implementation of the strategy
- the National Service Framework (NSF) for Mental Health did not adequately address the needs of parents with mental health difficulties, and there is much scope for improvements in policy and services in this area

- direct payments can provide parents with the flexible support they need, but much work remains to be done to increase the number of parents receiving direct payments, particularly among those with learning difficulties and those with mental health support needs
- disabled parents experience unequal access to health and other mainstream services (including maternity services) for parents and their children
- current disability benefits do not take account of the additional costs of parenting for disabled adults
- there is an urgent need for research that tells us more about the numbers and needs of disabled parents, and about ‘what works’ in terms of providing support to them and their children.

The full recommendations and explanations for them are to be found in the main report. The following are the key recommendations.

The Department of Health should:

- in consultation with organisations of disabled parents, develop a national protocol for the assessment of the needs of disabled parents, together with practice guidance on how best to meet their needs
- issue clear guidance that adult community care assessments should include the assistance that parents require with looking after their children
- develop a performance indicator on the take-up of direct payments by disabled parents
- take account of the needs and circumstances of parents with mental health difficulties when developing mental health policies
- fund research into examples of good practice in maternity services, develop protocols for maternity services to address the needs of disabled parents, and disseminate these to all maternity services
- encourage all health services which address the needs of parents to carry out disability audits of their premises, procedures and practices

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to ensure that they comply with the requirements of the Disability Discrimination Act 1995.

The Department for Education and Skills should:

- revise the *Framework for the Assessment of Children in Need and their Families* to:
 - take account of the support needs and entitlements of disabled parents
 - stress that it is inappropriate to assess parenting capacity without first assessing and addressing parents' entitlements to support under community care legislation
 - encourage social workers to challenge any negative attitudes they may hold and to fill any gaps in their understanding of the issues facing disabled parents
- amend *Working Together to Safeguard Children*, to require social workers to ensure that disabled parents receive assessments of, and responses to, their need for support under community care legislation before decisions are made about the capacity of parents to look after their children
- work with local education authorities and the Disability Rights Commission to encourage schools to fulfil their obligations under the Disability Discrimination Act with respect to disabled parents' access to schools and to communication between schools and parents.

The Commission for Social Care Inspection should:

- adopt a standard for the inspection of adults' and children's services which requires that disabled parents are enabled, where possible, to bring up their children and that social care organisations can demonstrate that, where children are unable to live with their parents, this is not as a result of lack of support.

The Valuing People Support Team should:

- in consultation with organisations representing disabled parents, ensure that the needs and experiences of parents with learning difficulties are addressed in all the initiatives taken to implement the national learning disability strategy.

The Independent Living Fund (ILF) should:

- amend the ILF Trust Deed so that support with ‘family roles and responsibilities’ can be included in the needs that can be met by an ILF grant.

The Department of Health, the ADSS and the Social Care Institute for Excellence (SCIE) should jointly consider:

- how to increase knowledge and understanding of ‘what works’ in supporting disabled parents
- how to increase knowledge and understanding among social care managers and practitioners of good practice in the use of direct payments by disabled parents, across all the different service users groups.

The Department for Work and Pensions should:

- in consultation with organisations representing disabled parents, carry out a review of how well the benefits system meets the needs of disabled parents and their families.

The ADSS should:

- encourage social services authorities to develop protocols for the assessment of the needs of disabled parents, in consultation with organisations of disabled parents
- disseminate information about the information and other services provided by the National Centre for Disabled Parents to all social services departments

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- work with the DPN to ensure that the *Disabled Parents' Rights and Services Handbook* is widely disseminated when it is published in 2004.

Social services authorities should:

- in consultation with organisations of disabled parents, develop protocols for the assessment of the needs of disabled parents
- promote direct payments for disabled parents
- examine the operation of their charging policies in terms of how they affect disabled parents, and make any changes required to ensure that they do not create perverse incentives for disabled parents to identify their children as being 'in need' or as 'young carers'
- examine procedures and policies for joint working across children's and adults' services to ensure appropriate referrals and that children do not become 'young carers' or are taken into care as a result of a lack of support to disabled adults.

Organisations involved in developing and delivering training for relevant health and social services professionals (qualifying and post-qualifying) should:

- include disability equality training within their training programmes
- cover issues relating to disabled parents, and include their entitlements under community care legislation and the Disability Discrimination Act
- consult with disabled parents' organisations about the content and delivery of such training.

Parent support organisations should:

- consult with disabled parents and organisations advocating on their behalf as to how they can better address the needs of disabled parents

- carry out an access audit of their services to ensure that they are accessible to disabled parents and fully comply with the Disability Discrimination Act
- ensure that such information and advice addresses the concerns of disabled parents, including black and minority ethnic parents
- provide Disability Equality training for their staff and volunteers, and involve disabled parents' organisations in the delivery of such training.

The Judicial Studies Board and those responsible for legal services should:

- take steps to ensure that the approach of all those involved in providing legal services should be based on an informed appreciation of disabled parents' situation, rights and entitlements for support. This is particularly important with respect to adoption, care, contact and residence applications.

1 Introduction

In the year 2000, the Department of Health's Social Services Inspectorate (SSI) concluded that, while providing support to help parents bring up their children is at the heart of the government's family policy, this is still a 'pipe dream' for many disabled parents (Goodinge, 2000, p. 1). For some years, disabled parents themselves had been arguing that inaccessible and inadequate services, and a lack of support, create problems for them and their children. It is not impairment, learning difficulties or mental health needs that are primarily responsible for the difficulties they face. Instead, it is negative attitudes towards disabled parents and unequal access to support that too often undermine family life.

This focus on disabling barriers was at the core of the approach taken by the Task Force on Supporting Disabled Adults in their Parenting Role. Set up in 2000 with the support of the Joseph Rowntree Foundation, the main participating organisations were the Disabled Parents Network (DPN), Disability, Pregnancy and Parenthood *international*, the Department of Health and the ADSS.

Members of the Task Force (who are listed in Appendix 1) share a common concern that, while progress has been made in recognising the rights of disabled people to be parents, both parent support services and community care services still fail to address the needs of disabled parents adequately.

At its first meeting, the Task Force set itself the following goals:

- to raise awareness across the statutory and voluntary sectors of the issues facing disabled parents and to foster the development of strategies to address these issues
- to shift thinking in social services authorities away from a narrow focus on children, and to build commitment and provide tools to address the divisions between children's and adults' services
- to produce targeted publications to inform, challenge and change the attitudes of professionals such as teachers, lawyers, health visitors and social workers, making links to the Human Rights Act

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- to produce information for disabled parents on their entitlements
- to get disabled parents onto the agenda of mainstream parent and family support organisations and projects
- to get disabled parents onto the agenda of mainstream disabled people's organisations and projects
- to ensure that the government initiatives such as the Children and Young People's Unit, the Children's Fund, Sure Start and Connexions do not undermine disabled parents
- to encourage the Department of Health to issue guidance on how to support disabled parents.

Progress has been made in most of these areas. Initiatives associated with, or relevant to, the work of the Task Force are listed in Appendix 2. The purpose of this report is to highlight the issues raised by the Task Force, put forward recommendations and bring the concerns of disabled parents to the attention of policy makers, service providers and individual practitioners.

2 Background to the Task Force

More than 20 years ago, in 1982, the National Childbirth Trust set up a disabled parents' support network, ParentAbility. During the late 1980s, an advocacy project, based at RADAR and run by John Keep, supported a number of disabled parents who were experiencing difficulties in accessing the assistance they needed in their parenting role. A coalition of organisations concerned with this issue, Parents Too!, was formed following a meeting convened by John Keep with ParentAbility and a number of impairment-specific organisations.

The Maternity Alliance established a Disability Working Group in 1989, followed by a Conference in 1992, a survey of disabled mothers' experiences (Maternity Alliance, 1993a) and the publication of a Charter for disabled parents and parents-to-be (Maternity Alliance, 1993b). At about the same time, the Department of Health's Expert Maternity Group identified negative attitudes and unequal access to services experienced by disabled parents and prospective parents, urging that action be taken to overcome 'the obstacles which confront them' (Department of Health, 1993).

A journal, *Disability, Pregnancy and Parenthood international* was started in 1993, to provide a forum for disabled parents and health and social care professionals to share experiences and good practice, and to disseminate research, publications and conferences. Demand generated by the journal led to the opening by DPP of an information service in 1998 (details of which are given in Appendix 3).

There were particular challenges, during the 1990s, to the widespread negative assumptions about parents with learning difficulties, and parents with mental health difficulties. A survey carried out by MIND found that almost four out of ten parents with mental health difficulties felt their ability to look after their children was unfairly questioned (Read and Baker, 1996). Ann Craft's work on parents with learning disabilities highlighted how any problems with parenting were exacerbated by poverty, inadequate housing, harassment and anxiety about losing a child into care (Craft, 1993). Research on the experiences of children of parents with learning difficulties found that parenting competence was

linked to the amount of support available from family and social networks rather than parents' impairment (Booth and Booth, 1997).

The increasing numbers of people with learning difficulties living in the community, rather than in long-stay hospitals, means that more are likely to become parents. Too often, however, the first contact that parents with learning difficulties have with health and social services is at a child protection case conference. Following one such case, Sue McGaw set up a 'Special Parenting Service' in Cornwall in 1988, with the aim of providing a multi-disciplinary service to assist parents with mild to moderate learning difficulties to look after their children. Throughout the 1990s, a few similar services were set up in other parts of the country. As one service provider wrote, 'What we needed was an automatic process of assessment, not about the risks to the child in a child protection context but about what was needed to enable the child to stay with the parents' (Jackson, 1998). The Maternity Alliance also launched a 'Right from the Start' Project, which aimed to raise awareness among maternity services of the needs of parents with learning difficulties.

By the end of the 1990s, the views and experiences of disabled parents – and specifically the difficulties they were having getting support to carry out their parenting role – were beginning to be heard (e.g. Wates, 1997; Wates and Jade, 1999). One project, which provided a support network for parents with learning difficulties, heard what a difference it could make to have an advocate: 'She explains to me what I don't understand, what social services are talking about ... Any problems, I tell her and she tries to help me' (Booth and Booth, 1998). There were also a few high-profile cases such as that of Penny Roberts, whose local authority initially planned to take her baby into care rather than provide the practical assistance she needed as a wheelchair user (*The Guardian*, 4 September 1998).

Towards the end of the 1990s, the support needs of disabled parents also started to be acknowledged by those organisations and researchers focusing on 'young carers'. As two of the key researchers in the field wrote: 'It is the absence of family-focused, positive and supportive interventions by professionals, often combined with inadequate income, which cause the negative outcomes associated with

caring by children and young people' (Dearden and Becker, 2000, p. 43). Moreover, children's charities that had funded 'young carers' projects increasingly shifted their emphasis towards supporting disabled adults in their parenting role, recognising this to be key to the welfare of their children (Olsen and Wates, 2003).

The DPN was formed in 1999 from the merger of ParentAbility and Parents Too!, and worked in close collaboration with DPP/. In 2000, funding was made available by the Home Office to set up the National Centre for Disabled Parents, jointly run by DPP/ and the DPN. This is a resource centre providing an information and advice service, training and consultancy, and a disabled parents support worker (see Appendix 3 for contact details).

In 1999, following a meeting between Parents Too! and inspectors from the Department of Health, the SSI carried out an inspection of services to disabled parents in eight local authority areas. The standards adopted by the SSI provided an important encouragement to make improvements in statutory services, and were welcomed by organisations representing disabled parents (see Goodinge, 2000, Appendix A). Their report, *A Jigsaw of Services*, identified gaps in services to support disabled parents, with 'a lack of co-ordination of services provided, time delays and limited appreciation of the necessity for services to meet the needs of the whole family' (Goodinge, 2000, p. 5).

This, then, was the background to the setting up of the Task Force in December 2000.

3 Issues identified by the Task Force

Information, advice and peer support

Disabled parents on the Task Force stressed the importance of information and advice and also how valuable it can be to have contact with other disabled parents. The information service run by DPP/at the National Centre for Disabled Parents receives enquiries from disabled parents about a range of issues, including:

- how to manage child care tasks and what equipment might be available or could be adapted
- negative attitudes of friends, families and professionals when a disabled person has become, or is about to become, a parent
- getting access to appropriate maternity services
- how to get assistance with child care tasks and support with parenting
- information about the implications of particular impairments for pregnancy and parenthood, and the impact of pregnancy and parenthood on particular impairments
- examples of good professional practice
- advice and support when social services have instituted child care proceedings and the parent may lose, or has already lost, their child/ren.

Many of the health and social services professionals who come into contact with disabled parents do not have relevant specialist expertise. The National Centre for Disabled Parents is therefore also an important source of information and advice for professionals.

Individuals such as John Keep, a disabled parent and now grandparent himself, have acted as unpaid advocates for other disabled parents and have provided crucial peer support. It is clear, however, from both the Centre's experience and from that of the disabled parents on the Task

Force that many disabled parents do not get access to the information and advice they need at the time they need it. As DPP's information officer said: 'Often parents are exhausted having been to a great many different services, organizations and agencies trying to get the right information and we often wonder "how did things get to this point?"' A consultation exercise carried out by the DPN in 2002, involving over 150 disabled parents, confirmed that getting hold of information was extremely difficult and time consuming (Wates, 2003). Parents reported that it was particularly hard to obtain information at a time when a family's needs changed suddenly.

In 2001, the DPN and DPP secured funding from the Home Office for a disabled parents support worker, and the DPN also received funding from the Department of Health to produce a *Disabled Parents' Rights and Services Handbook*. Evidence from both disabled parents and professionals indicates that such resources will be invaluable and need to be widely available.

Disabled parents told the Task Force that the voluntary organisations seeking to provide advice and support on parenting could do better at opening up their services to disabled parents. The Joseph Rowntree Foundation funded two initiatives. One was with the Parenting Education and Support Forum (PESF), who set up an e-mail group for professionals, and also held meetings with disabled parents to discuss how the Forum can better meet their needs. The other initiative was with Parentline Plus, who held a meeting with disabled parents to discuss how the organisation can address their concerns. The Foundation has also funded the National Family and Parenting Institute to find out about the kind of support that disabled parents have found, or would find, helpful. Details of these initiatives are in Appendix 2.

Advice and information services are covered by the Disability Discrimination Act 1995, yet it was clear to the Task Force that, in many instances, organisations were not fulfilling their obligations under the Act.

Recommendations

- All parent support organisations should consult with disabled parents and organisations advocating on their behalf as to how they can better address the needs of disabled parents.
- All parent support organisations should carry out an access audit of their services to ensure that they are accessible to disabled parents and fully comply with the Disability Discrimination Act.
- All organisations providing information and advice for parents should ensure that such information and advice addresses the concerns of disabled parents.
- All parent support organisations should provide Disability Equality training for their staff and volunteers. Disabled parents and their organisations should be involved in the delivery of such training.
- The ADSS should disseminate information about DPP's information service and the DPN's peer support network to all social services departments.
- The Department of Health and ADSS should work with the DPN to ensure that the *Disabled Parents' Rights and Services Handbook* is widely disseminated when it is published in 2004.

Disabling attitudes

The Task Force received evidence that disabled parents commonly face the assumption that their impairment or illness *in itself, and inevitably,* leads to child deprivation, potential harm or abuse. In contrast, Task Force members argued for an approach which recognises that these risks are created and/or exacerbated by the lack of appropriate support, unequal access to mainstream services, negative attitudes, and the poverty and poor housing which can be associated with physical/sensory impairments, learning disability and mental health difficulties.

This was also the message at a seminar organised by the Department of Health about parents with learning difficulties in the year 2000. Participants were told how advocacy and support can enable people with learning difficulties to be good parents.

The court recommended I work with the Circles Network so I could keep my children. It was nice to have someone listen to me, just for me, to help me. They didn't judge me. I was relieved, positive and knew things would change. The Circles Network facilitator was the first person to ask me, 'What do you want?' It made a big difference. (Jackie's Story, *Disability, Pregnancy and Parenthood international*, October 2001, p. 5)

Social work attitudes and practice

The importance of challenging attitudes held by some social work practitioners was raised many times by members of the Task Force, particularly by those who are disabled parents. Disabled parents experience anxiety and stress as a result of the tendency of some social workers to question whether disabled parents can look after their children properly. This type of attitude can also result in inappropriate service responses.

My social worker did not do much to help me. I think she had already decided that I could not cope ... I felt that nobody listened. (Sally's story, *Disability, Pregnancy and Parenthood international*, October 2001, p. 4)

Task Force members generally felt that there are two main focus points for a change in attitudes among social workers:

- The tendency to think of disabled parents as being in need of *care* rather than in need of *assistance* is disabling and undermines their role as parents. Organisations of disabled people have stressed that independence is not about doing everything for yourself, but about having choice and control over the assistance required to go about one's daily life. This understanding of independence needs to be applied to parenting tasks. Language is a manifestation of attitudes and, for example, if the word 'care' was replaced with the word 'assistance', this would indicate a change in approach to the needs of disabled parents.
- Perhaps the biggest hurdle faced by disabled parents is the deep-seated assumption that their children would be better off with non-

disabled parents. Social workers – and society generally – need more examples of the positive outcomes when disabled parents are supported to look after their children.

Recommendation

- Social work training, both qualifying and post-qualifying, should incorporate issues relating to disabled parents, and include their entitlements under community care legislation. Disabled parents' organisations should be consulted about the content and delivery of such training.

Legal professionals

Task Force members also identified that many members of the legal profession have little contact with disabled parents until they are involved in situations where a parent is already at risk of losing their child. Not surprisingly, solicitors, barristers and judges can hold the same negative attitudes about disabled parents as are common in our society.

The Task Force heard anecdotal evidence from the Family Rights Group advice line, the National Centre for Disabled Parents and other Task Force members about child protection cases proceeding to court without the support needs of the disabled adults even being assessed. As a result of this evidence, the Joseph Rowntree Foundation has funded Alison Richards of the Family Rights Group to raise awareness among legal services professionals through legal media of the rights and entitlements of disabled parents, in conjunction with disabled parents and organisations involved in supporting them.

Recommendation

- The Judicial Studies Board and those responsible for legal services should take steps to ensure that the approach of all those involved in providing legal services should be based on an informed appreciation of disabled parents' situation, rights and entitlements for support. This is particularly important with respect to adoption, care, contact and residence applications.

Any initiative which seeks to challenge attitudes towards disabled parents must recognise that Black and minority ethnic, and gay and lesbian parents face additional negative attitudes. As one disabled parent told the Task Force:

I feel they fob me off immediately they hear my name and accent. I was told I wasn't entitled to a community care assessment. I then found out, from another disabled person, that I was entitled to an assessment and she came with me as an advocate.¹

The legislative and policy framework

Disabled adults' entitlements to support under community care legislation

The Task Force focused mainly on the support that disabled adults need in their parenting role. However, disabled people also sometimes face barriers to accessing support to meet their own needs for assistance. This can impact on their role as parents, and can be a crucial factor in the identification of their children as 'young carers'.

Disabled parents and their organisations have long argued that, if they received the assistance and equipment they need to go about their daily lives, then they would not have to rely on their children to assist them. It is when disabled parents have not been able to access the support to which they are entitled that their children have been labelled as 'young carers'. The Task Force heard from parents that this is an inappropriate and unhelpful response for both themselves and their children.

Disabled people are entitled to receive an assessment of their needs and, if they meet the local authority's eligibility criteria, to have those assessed needs met. They are also entitled to be offered direct payments in lieu of services. Yet the Task Force heard evidence of situations where children are identified as 'young carers', and the only help the family is offered concerns enabling the child to carry on being a 'young carer'. Evidence was also heard of situations where children have been removed from their parents, without an assessment of any sort being offered to parents in terms of their own support needs.

As the condition progresses I can do less and less and I've ended up having to rely on my son to do things for me. I wish I didn't but social services don't seem to have anything to offer except a 'young carers' group for my son.

Recommendation

- Social services departments should develop protocols which require that, wherever a child is identified as a 'young carer', their parent is offered an assessment of their own needs for assistance and equipment.

This issue – of ensuring that disabled parents receive their entitlement to support to meet their own needs – is also reflected in some of the other recommendations set out in this report.

Community care legislation and the Children Act

A key issue identified was whether disabled parents can access the assistance they need without their parenting capabilities being called into question, or their children being considered to be at risk. In other words: can assistance with parenting tasks be accessed through disabled people's entitlements under community care legislation? Or is assistance with parenting tasks only available through the Children Act?

In order to access assistance under the Children Act, a child has to be considered to be 'in need'. Many parents feel that there is a stigma attached to this: there is an association with 'child protection'. Moreover, as an experienced social worker told the Task Force, family support (through Children Act services) may be available when child protection procedures are initiated because a child is considered to be 'at risk', but support is then withdrawn when the child is no longer considered 'at risk' (or when a child is removed from the parent's care). Disabled adults' perspective is that they require assistance in order to carry out parenting tasks, that this need for assistance is likely to be ongoing, and that the need is related to their experience of impairment and disabling barriers, not to their child being 'at risk'. Therefore, eligibility for such support should not be related to identifying that their children are at risk of harm.

Carers UK told the Task Force that disabled parents often find it easier to access funds for ‘young carers’ services than support for them in their parenting role. Moreover, parents are likely to be charged if they access support from adult services but will not be charged for ‘young carers’ services. There is therefore a perverse incentive to identify the children of disabled parents as being ‘in need’ as ‘young carers’. Yet, disabled parents say this both distorts the real issues and stigmatises their families, and therefore many are reluctant to ask for help.

It is helpful that new government guidance on ‘adult social care’, *Fair Access to Care Services* (FACS), includes ‘family and other social roles and responsibilities’ in the eligibility criteria laid out by the guidance (Department of Health, 2002a). Community care assessments should, therefore, include the assistance that someone might need with parenting tasks. However, it remains unclear as to whether assistance with parenting can be accessed *entirely* under community care legislation or whether the need for such assistance would inevitably trigger an assessment under the Children Act.

When the Department of Health issued practice guidance in the form of questions and answers, the situation remained unclear. The emphasis was on the need for adults’ and children’s social work teams to work together and reinforced the impression that, if a disabled parent requires assistance with parenting tasks, this would trigger a Children Act assessment (Department of Health, 2002b). Appendix 2 includes a proposed re-wording of this practice guidance by the DPN. It is helpful that the ADSS confirmed in a meeting with the DPN, held on 7 February 2003, that the ‘focus of services [to disabled parents] should come from the adults’ sector’. However, the Task Force heard much evidence that this is not always the case in practice.

Recommendations

- The Department of Health should adopt the re-wording of the FACS Questions and Answers proposed by the DPN.
- The Department of Health, in consultation with organisations of disabled parents and the ADSS, should develop a national protocol for the assessment of the needs of disabled parents, together with practice guidance on how best to meet their needs.

- In the absence of, or prior to, implementation of the above recommendation, social services authorities should, in consultation with organisations of disabled parents, develop protocols for the assessment of the needs of disabled parents. Such protocols should make clear that, when needs relating to ‘family and social life’ are assessed using FACS eligibility criteria, this should include any assistance required with parenting.
- Social services authorities should examine the operation of their charging policies in terms of how they affect disabled parents, and make any changes required to ensure that they do not create perverse incentives for disabled parents to identify their children as being ‘in need’ or as ‘young carers’.

Valuing People: a national strategy on learning disability

Valuing People, the national strategy on learning disability launched in 2001, contained a commitment to support parents with learning disabilities (Department of Health, 2001, Sub-objective 7.4). However, this is not an issue which has, so far, been tackled in the implementation of the strategy. For example, maternity services are not mentioned in the good practice guidance on health action plans (Department of Health, 2002c); support to parents with learning difficulties is not mentioned in the guidance for Learning Disability Partnership Boards on implementing Person Centred Planning (Department of Health, 2002d); and parenting is not mentioned at all in the guidance on Person Centred Planning (Department of Health, 2002e). However, we understand that the Valuing People Support Team is to turn its attention to parents with learning disabilities in the next stage of implementation.

It is helpful that the Inspection Standards adopted by the SSI in 2001 included the Standard, ‘Parents with learning disabilities are enabled, where possible, to bring up their children. Where children are unable to live with their parents, social services can demonstrate this is not as a result of lack of support’ (Social Services Inspectorate, 2001).

Recommendations

- Support to parents with learning difficulties should be addressed in all the initiatives taken to implement the national learning disability strategy, *Valuing People*.
- The Valuing People Support Team should, in consultation with organisations representing disabled parents, produce guidelines for local Learning Disability Partnership Boards to address the needs of parents with learning difficulties.
- All social services departments should be made aware of the above Inspection Standard and this Standard should be incorporated in the work of the new inspection body, the Commission for Social Care Inspection.

The National Service Framework for Mental Health

While the NSF for Mental Health (Department of Health, 1999) mentions the type of support services which can help mothers with young children, there is very little on how people with mental health support needs can be assisted to fulfil their parenting role. Joint working with children's services is only mentioned in a child protection context. Members of the Task Force felt that the NSF was a missed opportunity to address the support needs of parents with mental health difficulties.

A summary of research concerning parents with mental health difficulties, published in 1998, highlighted the difficulties that are caused when adult mental health services and children and families services do not work together (Falkov, 1998). Parents who experience mental health difficulties commonly have difficulties getting access to mental health services until they experience a crisis in their mental health. Hospital services, after-care services and individual care plans do not always address the need for support with parenting. At the same time, when a parent's difficulties come to the attention of child protection professionals, they are not always able to access support from adult mental health services. In this kind of situation, the focus remains on parental capacity, and the parent is in danger of losing their child/ren without receiving the support they need from adult mental health services.

In 1999, researchers based at the National Institute for Social Work were commissioned by the Department of Health to carry out a research and development project looking 'at the interfaces within and between services for families where a parent has a persistent mental health, alcohol or drug problem'. An initial report examined social services departments' policies and protocols for delivering services to this group of parents and their children (Kearney *et al.*, 2000). The second phase of the work, now at the Social Care Institute for Excellence (SCIE), devised a template for the development of collaborative work between agencies and families, based on the details of good working practice provided by local authorities and in Department of Health policy documents (Kearney *et al.*, 2003). The SCIE is also running practice development events for children's and adults' services, and hopes that the local agencies that attend will bring service users with them. The aim is to help children's and adults' services plan ways in which they can offer integrated and quality services to families where children live with parents who misuse alcohol or drugs, or have mental health problems.

Many of the recommendations already identified from the Task Force's work would address the needs and experiences of parents who have mental health difficulties. Additional recommendations were identified as set out below.

Recommendations

- The needs of parents who experience mental health difficulties should be considered when developing mental health policy and developing services, at both national and local levels.
- Those involved in such policy and service developments should consult with parents who experience mental health difficulties about their experiences and the most effective ways of meeting their needs and those of their children.
- The Commission for Social Care Inspection should adopt the following Standard when inspecting mental health social services and children's services, 'Parents with mental health support needs are enabled, where possible, to bring up their children. Where children are unable to live with their parents, social services can demonstrate this is not as a result of lack of support.'

Framework for the Assessment of Children in Need and their Families

The *Framework for the Assessment of Children in Need and their Families*, issued by the Department of Health in 2000 and commonly known as the Assessment Framework, has very little recognition of the needs and circumstances of disabled parents. For example, attention is drawn to research which found that children of parents with mental health difficulties are more likely to be involved in child protection proceedings, and it is inferred that parenting capacity in these circumstances is the only issue for practitioners. Parents told the Task Force that professionals using the Assessment Framework should also consider the impact of a lack of support, and of inappropriate services, on parents and families.

Two members of the Task Force, Richard Olsen and Michele Wates, have written a detailed critique of the Assessment Framework in terms of how well it addresses the needs and experiences of disabled parents. They write:

Discussion of parental disability throughout the document centres around discussion of its potential impact upon the disabled adult's parenting *capacity* and *responses* rather than considering how best to tackle barriers to social inclusion and address parental support needs. This isolation of the 'parenting capacity' of disabled adults as if it were an individual characteristic, separable from environmental, social and organisational contexts, may have an effect that is counter to the integrative aims of the *Framework*.

In the *Framework* practice guidance there is extensive discussion of the impact of socio-economic factors such as housing, family social integration, employment and income, and so on, *in relation to disabled children*. Unresolved difficulties in these areas will have an equally substantial, and in some cases even greater, impact on children's welfare where it is the *parent* rather than the child who has the impairment. Yet neither the policy nor the practice guidance issued as part of the *Framework* directs the attention of assessors using it to family and environmental factors affecting families in which a disabled adult is present.

(Olsen and Wates, 2003)

There is also no recognition in the Assessment Framework that practitioners may approach disabled parents with inadequate knowledge or negative attitudes. While practitioners are encouraged to take a critical approach to elements in their practice that might create or exacerbate difficulties experienced by families from minority ethnic communities, there is no encouragement to do this in respect of disabled parents.

Recommendations

- The Department of Health should revise the Assessment Framework to:
 - take account of the support needs and entitlements of disabled parents
 - stress that it is inappropriate to assess parenting capacity without first assessing and addressing parents' support needs
 - encourage social workers to challenge any negative attitudes they may hold and to fill any gaps in their understanding of the issues facing disabled parents.
- The Commission for Social Care Inspection should adopt the following Standard when inspecting children's services, 'Disabled parents are enabled, where possible, to bring up their children. Where children are unable to live with their parents, social services can demonstrate this is not as a result of lack of support.'

Support services

The Task Force generally felt that there is better recognition now, at national government level, of disabled parents as a specific group of people who have important and legitimate support needs. The Task Force also welcomed the government's policy that promoting children's well-being and keeping them safe should be achieved, wherever possible, by providing support to parents. The emphasis on joint working across departments and agencies is also helpful. At a local level, there are some examples of good practice in using community care legislation and direct payments to ensure that disabled parents receive the flexible and empowering support they need in order to look after their children.

The key question, however, as one Task Force member said, is 'how to make this approach accessible to all disabled parents, wherever they live'. Although this section deals with support services provided by local authorities, it is also important, as mentioned above, that mainstream parent support organisations in the voluntary sector address the needs of disabled parents.

Community care services

Unfortunately, the Task Force heard many accounts from disabled parents of inflexible, inaccessible and less than adequate support services. There is also evidence that Black and minority ethnic disabled parents experience high levels of unmet needs and that, when services are provided, they are not always culturally appropriate (Jones *et al.*, 2002).

Disabled parents told the Task Force that delays in accessing and receiving support could have a significant impact on their and their children's welfare. They gave examples where help was not available until their family was on the point of breaking down.

I asked for a community care assessment that never happened. At the time I got nothing. Even with the emergency team there was so much delay they weren't there when I needed them. But now they have turned it around and are telling me all the things I have to do to keep my kids.

Many parents feel that they are up against a brick wall when they seek support that might prevent any problems arising.

I was told that there was no funding for adapted equipment or support for disabled parents with children. I was told to ring back after I had the baby.

Particular concerns were expressed about parents who were labelled as having 'mild to moderate learning difficulties' and therefore did not fit the eligibility criteria of adult learning disability support services. Parents can find that social services will only respond when their children are

identified as 'at risk'. One parent told the author of this report that her local Learning Disability Team informed her that she did not qualify for help from them, while the Children and Families Team said they would assess her if she thought she was not coping. She did not want to say this, because she was afraid they would take her children away.

Fears that children may be taken into care if parents contact social services can be compounded by uneasy relationships with social workers.

The more I felt criticized the less able I was to get on with things ...
Community care tended to judge me. They said if you don't get your act together you will lose your kids.

Black and minority ethnic parents told the Task Force that they experienced particular fears that racism, combined with negative attitudes towards disabled parents, would result in their losing their children into care. They stressed that there was therefore a need for reassurance that they would not be faced with such negative attitudes. If this reassurance is not available, it is likely that many Black and minority ethnic parents will be deterred from seeking the assistance to which they are entitled.

Parents commonly find that services provided for disabled adults do not take account of the fact that some are parents. One disabled mother was offered transport provided from a voluntary sector group to take her shopping, but the organisation initially refused to let her take her children with her.

It was all agreed and everything was fine and then they phoned me back and said they couldn't take children as passengers on insurance grounds. So they had assumed people don't have children. I argued with them and in the end they said yes you can bring your children but only because you are a single parent, which I thought was a strange thing to say.

The Task Force brought together researchers and voluntary organisations whose focus was on 'young carers' with those whose

focus was on disabled parents. This was a reflection that over the last few years there has been increasing recognition that supporting disabled adults in their parenting role is the key to safeguarding the welfare of their children. Indeed, anecdotal evidence suggests that many 'young carers' projects seek to support parents by assisting them to get access to community care and other services.

Disabled parents told the Task Force that services which identify their children as 'young carers', without addressing parents' support needs, are undermining their family life. Some feel that the proliferation of 'young carers' projects institutionalises the failure of services to provide the support that parents needed.

Recommendations

- Parents should be able to access support services without fearing that their children will be seen as 'in need' or 'at risk', and without having to label their children as 'young carers'. Particular attention needs to be paid to reassuring Black and minority ethnic disabled parents that they will not be faced with the combination of racism and negative attitudes towards them as disabled parents.
- Community care assessments should include the assistance that parents require with looking after their children.
- Assessments should identify needs, and should not be limited to assessing eligibility for existing services.
- Assessments and services should not focus on what parents cannot do as a result of impairment but on how environments can be changed and equipment and support provided to enable them to look after their children.
- Assessments and services should recognise that most disabled parents have expert knowledge about the impact of their impairment and of disabling barriers, and what would help them look after their children.
- Social services departments should ensure that those who carry out community care assessments receive training about how to

assess for needs associated with parenting tasks. Such training should be planned and delivered in partnership with disabled parents and their organisations.

- Community care assessments and services should be able to respond to situations where the disabled person's needs would not usually meet current eligibility criteria (for example people with 'mild or moderate learning difficulties') but where a failure to meet needs for support associated with parenting roles would threaten the family unit and relationships.
- The Department of Health, the ADSS and the SCIE should jointly consider how to increase the knowledge and understanding of 'what works' in supporting disabled parents.

Direct payments and disabled parents

Direct Payments have put me back in control of my life, I am now well supported.

Direct Payments have enabled me to employ my own home help and a local nursery to take my daughter to school. For me it means consistency of care and not having to explain yet again how I want things done.

For a number of years, disabled people have used cash payments in order to purchase the assistance that they need in a way that delivers choice and control in their lives. These payments are made by social services authorities, who can make cash payments in lieu of services to meet assessed need (under either community care legislation or the Children Act); and by the Independent Living Fund (ILF), who can make payments up to a maximum of £395 per week.

Since the publication of FACS guidance, social services should be considering 'family roles and responsibilities' when carrying out community care assessments. However, the Task Force was informed by the Director of Research at the ILF that the ILF's Trust Deed specifies that ILF grants can only be used to meet assessed needs for personal care and domestic assistance and not for child care or support needs related to parenting a child.

The ILF's Trust Deed states: 'Childcare costs cannot be covered. It is acceptable, however, that a service being provided for the disabled person be extended to include that person's child(ren), e.g. preparing a meal or laundering clothes. Time paid for by the Funds cannot, however, be used for collecting children from school. The test would be to ask what personal needs, as defined above, would need to be fulfilled if the child(ren) were not there.' While there would be ways of combining direct payments from a social services department with ILF grants in ways which met parents' holistic needs, this is an unfortunate limitation on the support that can be funded through ILF grants. It is also at odds with the inclusion, within FACS eligibility criteria, of 'family roles and responsibilities'.

A number of concerns were raised by Task Force members about direct payments. The Task Force welcomed the commitment, within the Health and Social Care Act 2001, to require local authorities to make direct payments available to those who qualify. However, take-up of direct payments generally remains very low, and there are wide variations in the practice of social workers and managers in terms of opening up the possibility of direct payments for disabled parents. Task Force members argued that there is a need for building knowledge and understanding about how direct payments could make a real difference.

There are particular concerns about how to encourage the use of direct payments by parents with learning difficulties and by parents who use mental health services. These are two groups among whom there has been a particularly low take-up of direct payments so far. Although the learning disability strategy, *Valuing People*, gave a commitment to increase the use of direct payments among people with learning difficulties, there has been no recognition so far, in the implementation of the strategy, of the potential of direct payments for parents with learning difficulties.

When the DPN met Jacqui Smith, at that point the relevant Minister within the Department of Health, she stressed that the government 'believed that the best way for [disabled people] to get support with parenting was through direct payments' and said that 'developing a Performance Indicator on the take-up of direct payments could be a possibility' (Note of meeting between Jacqui Smith and the DPN, 11 March 2003).

Recommendations

- The ILF's Trust Deed should be amended so that support with 'family roles and responsibilities' can be included in the needs which can be met by an ILF grant (in line with government guidance, FACS).
- Practice guidance on direct payments should include case study examples of direct payments being used by disabled parents, following community care assessments.
- The Department of Health, ADSS and SCIE should jointly consider how to increase knowledge and understanding among social care managers and practitioners of good practice in the use of direct payments by disabled parents, across all the different service users groups.
- The implementation of *Valuing People* should develop a strategy to enable parents with learning difficulties to use direct payments.
- The Department of Health should develop a Performance Indicator on the take-up of direct payments among disabled parents.

Local authority child protection and family support services

They tell you what you are doing wrong in a meeting. What they should do is sit down with parents and explain how to do it right. (Mary's Story, *Disability, Pregnancy and Parenthood international*, No. 36, October 2001, p. 3)

[Social services offered me] foster care for my children to give me a break from them! I didn't need a break from my children, I needed support, but no-one seemed to be able to help us. I was told that not only was I not entitled to direct payments but that I certainly couldn't have a package which would assist and support me in my role as a parent. I can't tell you how many times my children were assessed, by the children's team. And me assessed by the adults' team. But for some reason these two teams just didn't seem to work together ...

According to the 2001 Children in Need census, 5 per cent (3,400) of looked-after children and 5 per cent (8,500) of children supported within their family were 'in need' because of 'parental illness or disability' (Department of Health, 2002f). This report has already mentioned the difficulties with the *Framework for the Assessment of Children in Need and their Families* in terms of addressing the support needs of disabled parents. There is also no recognition in the inter-agency guidance on safeguarding children, *Working Together to Safeguard Children* (Department of Health *et al.*, 1999), of the importance of ensuring that disabled parents receive the support they need in order to look after their children.

I believe that they decided to take Jennifer away right from the start – not giving me a chance. I had her early and had to go to the case conference hours after giving birth to my daughter by Caesarean section.

(Mary's Story, *Disability, Pregnancy and Parenthood international*, No. 36, October 2001, p. 3)

Disabled parents told the Task Force that they felt many assessments are dominated by a focus on parental 'incapacity' instead of a focus on support, which would enhance parents' ability to look after their children. Task Force members said that family assessment centres can play a particularly important role for parents with learning difficulties, and it is vital that assessments address parents' support needs, including for advocacy and self-advocacy support. Concern was expressed that there are currently no minimum standards or regulation of the services provided by family assessment centres, unless they are residential.

During the assessment process I felt terrified most of the time, not listened to and annoyed.

(Jackie's Story, *Disability, Pregnancy and Parenthood international*, No. 36, October 2001, p. 5)

The new National Minimum Standards on residential family centres require that premises are equipped and adapted to meet the needs of a disabled parent or child and that support and information are available to suit particular needs, including parents with learning difficulties or mental

health difficulties (Department of Health, 2002g). However, there also seems to be an assumption (Standard 19.4) that only some centres will be accessible to disabled parents (or children), in spite of the fact that such services are covered by the Disability Discrimination Act.

Members of the Task Force felt that social workers require more training to work across the divide of adults and children. Lack of familiarity with the circumstances and experiences of disabled parents means social workers may sometimes have little understanding about the needs of parents and they and their children can be stereotyped as 'burdens' and 'victims'.

One social worker with extensive experience of working with disabled parents told the Task Force that 'most parents see the involvement of children's services as an indication that they are not looking after their children properly. This is even the case where parents do not fear that their children will be taken into care.' Early support, delivered in a non-judgemental and empowering way, however, can make all the difference to parents' ability to look after their children.

When I left the hospital with Chanelle I had a midwife coming to my place every day for 28 days. This was good because it helped me get a bond with her, because at first she did not feel like my own child because my first child got taken away at an early age. I had quite a lot of help with Chanelle when she was a baby and with her growing up. I had all the help I needed from social workers and nurseries.

Some parents, however, feel very strongly that professionals are not willing to listen to them.

They wanted me to change but they didn't want to listen to how I felt.

Some progress has been made in recent years. For example, Richard Olsen and Michele Wates told the Task Force about the workshops and seminars they have run, on developing good practice in working with disabled parents. These have been organised by SSI regional committees, Research in Practice, Making Research Count and the

Centre for Evidence-based Social Services. Participants have included adults' and children's services, carers and young carers' services, health, education and the voluntary sectors. They have generally welcomed a perspective that sees families as a whole, working supportively across community care, carers' and children's legislation, avoiding a narrow focus on children as 'young carers' or 'children in need'.

The Joseph Rowntree Foundation has funded the National Family and Parenting Institute to find out about the kind of support that disabled parents have found helpful, or would find helpful, in making parenting less difficult. Contact details for the project are in Appendix 2.

John Keep, from the DPN, told the Task Force of his concerns about current developments in children's and adults' services. The development of Children's Trusts and Primary Care Trusts and the recent movement of ministerial responsibility for children from the Department of Health to the Department for Education and Skills, may create an even larger gap between children's and adult community care policies than currently exists. Joint working between adults' and children's services may become more difficult, and disabled parents in contact with children's services – because their children have been identified as being 'in need' or 'at risk' – may find it harder to get assistance with their parenting role. In these situations, disabled parents are at risk of losing their children into care.

Recommendations

- *Working Together to Safeguard Children* and the *Framework for the Assessment of Children in Need and their Families* should be amended to require social workers to ensure that disabled parents receive assessments of, and responses to, their need for support under community care legislation before decisions are made about the capacity of parents to look after their children.
- Child-protection training for social workers should include information about the needs and entitlements of disabled parents and encourage social workers to challenge negative stereotyping of disabled parents. Disabled parents should be involved in designing and delivering training for social workers.

- Initiatives that seek to disseminate research and encourage evidence-based practice should continue to invite researchers and user-led organisations to present the perspective of, and findings from research about, disabled parents to seminars of social workers and other professionals.
- The Department of Health and the Department for Education and Skills should fund the dissemination of the perspective of, and findings from research about, disabled parents to social services (children and adults), health, housing and education professionals, and to mainstream parent education and support organisations.

Losing children into care

My two youngest daughters have been in care for eight years now. I have contact with them but I still miss them dearly.

Task Force members expressed concern that some disabled parents, particularly those with learning difficulties and those who were users of mental health services, have had children removed from home and taken into the care of the local authority without their support needs as parents ever having been assessed or addressed.

It was recognised that, particularly in the case of parents with learning difficulties, the adoption of a child by non-disabled parents can still be seen as the first, and preferable, option by some child care professionals. The Task Force was told of situations where care orders are taken without any involvement of specialist adult workers or any assessment of the parent's support needs. Indeed, once child protection concerns arise, this can be exactly the point when support to the disabled parent drops off the agenda. It is important that, if a child is removed on an interim care order or a supervision order is taken out, the parent's support needs are identified and met in order to maximise the chances of them being able to look after and keep their child.

The Task Force felt it especially important that social services departments address the situation where some parents (for example,

parents with mild learning difficulties) are turned away from services because their needs are seen as being below eligibility thresholds for adult community care services. Without support, some of these parents struggle to look after their children and, when they reach crisis point, their situation is responded to in terms of 'child protection'. It also needs to be recognised that many parents with learning difficulties whose children are taken into care then go on to have other children to replace the ones they have lost.

The seminar held by the Task Force in September 2001 heard from one parent with learning difficulties how the right support could keep a family together. During court proceedings, the Guardian Ad Litem had suggested that a families project run by Circles Network should become involved, and this provided the support the mother so badly needed.

For the first time I felt the support was for me ... they asked me what I wanted. The service drew up a relationship map that showed how isolated I was as an adult and that I had too many professionals in my life, that were not being any help ... We looked at ways in which things could be changed and the support that I would need to make those changes ... I feel like I can do things, I am more together, more tolerant with the kids ... We have more friends and less professionals now in our lives.

Recommendations

- The Department for Education and Skills should amend current guidance to require local authorities to demonstrate that they have assessed, offered and put in place support to disabled parents before the decision is taken to go to court at any stage in the child protection process.
- Local authorities should also be required to ensure that the support needs of disabled parents continue to be addressed once child protection procedures are instituted, including following any interim care or supervision orders.
- Resources should be made available for the development of advocacy services for disabled parents.

Poverty

There is little research on the socio-economic circumstances of disabled parents, but research on 'young carers' generally found poverty to be a common experience. One study of 60 young people found that 'virtually all the young carers' parents were in receipt of welfare benefits and were outside the paid labour market. Experience of poverty and social exclusion was common' (Dearden and Becker, 2000, p. 2). Secondary analysis of the General Household Survey (GHS) found that families with an ill or disabled parent were more likely to have an income below 50 per cent of median household income than families where there was no ill or disabled parent (Adelman *et al.*, 2001).

The Task Force was told that there is no benefit that takes into account the additional costs of being a disabled parent. When assessing the level at which Disability Living Allowance (DLA) should be paid, no account is taken of assistance needed with parenting tasks. Parents can get a Carers Allowance to contribute towards the additional costs of parenting a disabled child, but the additional costs of parenting because of parental impairment or ill health are not acknowledged within the benefit system.

A meeting was held with representatives of the DPN, DPP; the Disability Alliance and RADAR to discuss whether disabled parents have additional costs which should be taken account of within the DLA. Disabled parents identified that they had incurred additional expenditure on, for example: increased reliance on convenience foods; increased use of more expensive social activities (because cheaper options are inaccessible); paying for assistance to support parenting tasks; paying a support worker's costs when going out; costs of specialist or adapted equipment; increased transport costs; increased reliance on child care.

The meeting agreed to explore further the appropriateness and possibility of campaigning for an additional benefit for disabled parents, such as a parenting component of DLA.

Recommendation

- The Department for Work and Pensions should, in consultation with organisations representing disabled parents, carry out a review of how well the benefit system meets the needs of disabled parents and their families.

Health services

Following full implementation of the Disability Discrimination Act, all health services should be accessible to disabled people. Unfortunately, the Task Force heard of the continuing barriers to equal access faced by disabled parents. For example, one deaf parent reported:

I wanted to go to an ante-natal class but the classes are aimed at hearing people. They were talking about breathing on the video and this was not at all accessible to me ... there's not enough information for deaf parents.

As the outreach worker for a Deaf People's project identified, it is very important that midwives, clinical staff, maternity nurses and health visitors are aware of any particular support needs of parents and parents-to-be:

Any woman needs to develop a trusting relationship and good communication with the people who are to help her to deliver her baby safely. This is even more so for deaf women and women with learning disabilities. These women may find it harder to access normal channels of information and support during pregnancy and parenthood due to communication issues, and open or overt hostility or discrimination. Even where written English is not a problem they may have difficulty accessing support – e.g. attending ante-natal classes, NCT gatherings etc., or accessing parent support groups or telephone help lines.

A meeting held with disabled parents, set up by the Parent Education and Support Forum as part of the Task Force's work, was told of situations where initiatives to support parents of young children were not accessible to disabled parents. For example, one parent spoke of a

12-week course organised by health visitors, which was held in a venue inaccessible to wheelchair users; another described finding it difficult to participate at a baby clinic because the changing tables were too high.

The Task Force also heard evidence of some good practice: for example, one hospital has identified a member of staff whose job it is to check that disabled parents' needs are planned for and met appropriately. However, they also heard evidence of some hospitals where the maternity ward is the only ward that does *not* have facilities for disabled people.

The Task Force hoped to influence the standards on maternity services that will be adopted as part of the NSF for Children. A one-day seminar was held with representatives from the External Working Group on maternity services, and parents told of their difficulties in accessing services. The lack of accessible and up-to-date information was a key issue, as was the inaccessible environments and equipment in ante-natal, maternity and post-natal services. Again, parents identified that the attitudes of professionals could have a huge impact on experiences of services: a midwife who is willing to search out ways to make her service suitable for a disabled woman can make all the difference to that woman's experience of motherhood. The meeting was also told of one maternity unit that had used government funding for improving maternity units to make their unit more suitable for disabled parents. This included the purchase of suitable cots and labour beds, adapting examination rooms, toilets, reception areas and providing more disabled parking bays.

Recommendations

- Disability equality training (including challenging attitudes to disabled parents) should be part of both the initial professional training for midwives, health visitors, etc. and also in post-qualifying training. Disabled parents should be involved in designing and delivering training.
- All health services which address the needs of parents should carry out disability audits of their premises, procedures, practices and information to ensure that they comply with the requirements of the Disability Discrimination Act 1995.

- The Department of Health should fund research into examples of good practice in maternity services, develop protocols for maternity services to address the needs of disabled parents and disseminate these to all maternity services.
- The NSF for children should encourage hospitals and Primary Care Trusts to take steps to ensure equal access to maternity services for disabled parents.

Education

Disabled parents told the Task Force that it could sometimes be very difficult to fulfil their role as parent in the context of their children's education. Schools need to think about access for disabled parents – as they are required to do under the Disability Discrimination Act. This can mean physical access – like ramps, lifts, parking spaces, dropped kerbs, a choice of types of chair to sit on at meetings and so on. It can also mean accessible communication, such as asking parents in what format they would prefer school reports, whether they require Sign Language Interpretation at meetings with teachers, telephoning parents whose low energy levels mean they cannot come to meetings, and other examples.

Parents stressed that access is also about attitudes. Anti-bullying policies need to recognise that children are sometimes bullied because of ways in which their parents are seen to be different. Analysis of data from the Poverty and Social Exclusion Survey of Britain found that the children of ill or disabled parents were more likely to be bullied than other children and less likely to have access to play facilities and youth clubs (Adelman *et al.*, 2001). A survey carried out by MIND reported that a quarter of parents with mental health difficulties said their children had been teased or bullied because of their psychiatric history, or they were afraid they would be (Read and Baker, 1996).

My children were teased both at school and on the streets near home about my condition. I was referred to as a 'psycho'.
(Read and Baker, 1996)

At a policy level, the needs of disabled parents in the context of their relationship with schools and education authorities have only been recognised via the identification of children as 'young carers'. Some parents have reported that identifying their children as 'young carers' can mean that teachers have low expectations of their children's potential (Association of Disabled Parents in the Norfolk Area, 1995). Schools have been alerted to the possibility that perhaps 30 children in the average secondary school are 'young carers'. However, current guidance for schools does not do much more than acknowledge that social services authorities should be carrying out multi-agency assessments of children identified as being 'in need' (Department for Education and Employment, 1999, para. 2.5). Schools are encouraged to appoint a specific member of staff to deal with 'young carers' and refer children to 'young carer' projects. They are also warned that 'Referral to outside agencies should be done sensitively, recognising that a child may fear being "put into care" if the parents are seen as unable to cope' (Department for Education and Employment, 1999, para. 3.11).

The Department of Health has recently supported good practice guidance concerning working with 'young carers', published by The Children's Society and especially aimed at schools (Frank, 2002). However, Task Force members felt it was important that schools should be encouraged to develop good practice in their relationships with disabled parents. Disabled parents consulted by the DPN reported that many schools did not take any responsibility for ensuring that parents' meetings were accessible, or that written communication from school to parents was available in accessible formats (Wates, 2003). There is obviously a long way to go before schools fulfil their obligations under the Disability Discrimination Act.

Recommendations

- The Department for Education and Skills, local education authorities and the Disability Rights Commission should encourage schools to fulfil their obligations under the Disability Discrimination Act with respect to parents' access to schools and to communication between schools and parents.

- The Department for Education and Skills should develop a good practice guide for schools on how to promote good relationships between schools and disabled parents and to encourage disabled parents' involvement in their children's education.

The need for research

According to secondary analysis of the GHS (Adelman *et al.*, 2001), ill or disabled parents make up a quarter of families with dependent children. However, the definitions used for the GHS are open to criticism (as are the definitions used by other large data sets), and this secondary analysis was itself based on a sub-sample of the GHS. It is generally recognised that we do not know enough about the numbers and needs of disabled parents. This hampers both the development of appropriate policy and the planning of effective services.

The Task Force was told that there is an urgent need for research focused on supporting disabled parents. Michele Wates, from the DPN, argued that the lack of a strong, credible body of evidence about 'what works' in supporting disabled parents weakens the potential to influence policy development and increase the understanding of policy makers and practitioners. So far, most research has focused on 'young carers', and it is acknowledged that this may have resulted in some skewed policies and practices in supporting these children and their parents. The Task Force was told that research should involve disabled parents and their families, and should be able to answer the question 'How this will make a difference?' The DPN has called for quantitative research designed to provide specific information that could assist policy makers and practitioners.

Recommendation

- A Research Forum should be established, possibly facilitated by SCIE, to bring together researchers, key stakeholders (including disabled parents) and potential allies, to influence the research agenda, help disseminate research and influence change.

4 Conclusion

Much progress has been made in recent years in recognising the needs and experiences of disabled parents. The SSI Inspection, *A Jigsaw of Services*, was the culmination of representations made to government by disabled parents' organisations and marked a welcome intention to look at how things could be done better. Many of the concerns articulated by organisations representing disabled parents are in fact reflected in government priorities, in particular the policy that children's well-being should be promoted, wherever possible, by providing support for parents, but also the aim of community care policy to promote independent living and social inclusion. The inclusion of 'family roles and responsibilities' in the eligibility criteria for support under community care legislation is a welcome recognition that disabled people may also be parents. Acknowledgement of the common ground shared between organisations focusing on 'young carers' and those representing disabled parents also marks significant progress in an understanding of the daily realities faced by disabled parents, and how best to meet their and their children's needs.

However, much more needs to be done if we are to prevent situations where parents' own support needs remain unassessed and unmet, resulting in their children being identified as 'young carers' or being removed from their family. And we are still a long way from ensuring that disabled parents receive the support they need in order to carry out parenting tasks, thus ensuring their right, and that of their children, to a family life.

The Task Force has identified a number of improvements that could be made within the existing legislative framework for supporting disabled adults, and that for supporting children and families. If adopted, these recommendations would help to achieve the governments' aims of promoting independent living for disabled adults and enabling children, wherever possible, to be cared for by their families. The Task Force has also identified important steps that could be taken by parent support organisations in the voluntary sector to address the experiences of disabled parents better. There are other areas of disabled parents' lives that the Task Force was not able to pay full attention to, but which need

to be addressed in the future. These include the very important role that housing plays in enabling disabled people to live independently, and the need for schools to have a positive attitude towards disabled parents.

Perhaps the most important message from the Task Force is that, whenever policies and protocols are established, services developed or research designed, this must be done in partnership with disabled parents and organisations representing them. It has been the failure, in the past, to consult with and involve disabled parents, that has, all too often, resulted in inflexible, unhelpful services. Nevertheless, there are many examples of individuals working hard to meet the needs of disabled parents and their children, and some authorities are supporting this work. Throughout this report, the Task Force has identified recommendations which, if implemented, would build on this good practice and make a major difference to the lives of parents and children.

Note

- 1 Where quotes from parents are unattributed, they are either by parents who attended the event organised by the Disabled Parents Task Force in September 2001, or by parents who spoke of their experiences to the author of this report.

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Appendix 1: Task Force members and Terms of Reference

Task Force members

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Wendy Booth, University of Sheffield
Jabeer Butt, Race Equality Unit
Chris Dearden, University of Loughborough
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Clem Henricson, National Family & Parenting Institute
Jean Jackson, Parenting Education Support Forum
Ray Jones, Wiltshire County Council
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John Keep, Disabled Parents Network
Enid Levin, Social Care Institute for Excellence
Sue McGaw, Special Parenting Service, Cornwall Health Care Trust
Janet MacGeorge, Royal Borough of Kingston upon Thames
Rosaleen Mansfield, Disability Pregnancy and Parenthood *international*
Susan Moore, Disability Pregnancy and Parenthood *international*
Jenny Morris
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Dr John Newland, University College London
Richard Olsen, Nuffield Community Care Studies Unit, University of Leicester
Alison Partridge
Vicky Pearlman, Carers UK
Imelda Redmond, Carers UK
Alison Richards, Family Rights Group
Mary Robertson, Oxfordshire Social Services (since retired)
Patricia Smith
Noel Towe, Local Government Association
Helen Tyers
Michele Wates, Disabled Parents Network

Observers

Jeff Bashton, Department of Health

David Ellis, Department of Health

Wendy Hooper, Department of Health

John McCracken, Department of Health

Kevin Woods, Department of Health

Task Force Terms of Reference

At its first meeting, in December 2000, the Task Force adopted the following Terms of Reference:

- to promote a positive commitment to supporting disabled people in their parenting roles
- to promote working in partnership by relevant organisations and agencies to support disabled people in their parenting roles
- to promote recognition of the right to family life of disabled adults and the children of disabled adults
- to promote the provision of support that is holistic, co-ordinated and culturally appropriate, that meets the needs of all family members, and that reinforces the parenting role of disabled adults
- to promote key messages from the SSI report *A Jigsaw of Services* and other relevant research, and to monitor progress on the implementation of SSI recommendations in the development of local and national policy and practice
- to ensure that the experiences, findings and initiatives of disabled parents, the voluntary, academic and statutory sectors are shared
- to identify and find ways to address existing gaps in knowledge
- to work with and complement the Carers National Association Young Carers Initiative (Alliance of Voluntary Organisations)
- to work within an Equal Opportunities framework, taking explicit steps to address race equality and other dimensions of in/equality.

Appendix 2: Initiatives associated with, or relevant to, the work of the Task Force

1 Local authority policies and protocols

Michele Wates, from the DPN, was funded by the Joseph Rowntree Foundation to carry out a survey of social services departments' policies, protocols and service user information concerning disabled parents (Wates, 2002). One hundred and twenty-five (82 per cent) authorities responded and 31 (25 per cent) sent copies of policies and/or protocols. Parenting tasks were included in community care eligibility criteria in only a few authorities. There was generally a lack of clarity about how the assessment of children's needs would link with community care assessments. Only one authority had produced information specifically aimed at disabled parents.

Perhaps most significantly, the research concluded that neither community care nor children's legislation, policy and practice guidance was being used effectively to support disabled parents in their parenting role.

2 Joint consultation workshop on *Building a Strategy for Children and Young People*

The Children's and Young People's Unit (CYPUP), set up to help government Ministers, work together to develop policies to maximise children's life chances, published a consultation document in 2001 called *Building a Strategy for Children and Young People*. The Disabled Parents Task Force met with Carers UK Young Carers Alliance of Voluntary Organisations to consider the strategy from the point of view of disabled parents and their children. The main messages from the meeting were:

- There needs to be increased awareness, across all government departments, that it is the failure to meet the support needs of disabled parents that results in children and young people becoming 'young carers'. It should be acknowledged 'young carers' projects are

being relied on as compensation for health and social services' failure to address these unmet needs. It would not be helpful for children if more resources were directed at 'young carers' projects without action being taken to meet the support needs of their parents.

- There was concern about what was meant by the term 'local community', and questions were raised about who in the community decides what are the changes to be aimed for. Some families with disabled parents experience aspects of their local communities as hostile, excluding and disempowering. Children and adults may be subject to bullying and harassment; they may be excluded from participating in community groups and decision making through the failure of community leaders and organisations to give thought or effort to including them.
- As the CYPUP has a remit to work across government departments, they should seize the opportunity to encourage the different departments and professions to work together – from training through to service delivery – to address the needs of disabled parents and their children better.

3 Sharing good practice in working with disabled parents

The Joseph Rowntree Foundation funded the National Family and Parenting Institute to find out about the kind of support that disabled parents have found helpful, or would find helpful. The project has a website: <http://www.nfpi.org/disabledparents> and is due to publish its report early in 2004. The report will include examples of supportive practice from four local authorities in England and recommendations on how to improve local policy and practice.

4 *Disabled Parents Rights and Services Handbook*

Funding for this was received by the DPN from the Department of Health. The first stage of the project was to carry out a consultation with 150 disabled parents and the results of this are published by the DPN (*//*

Shouldn't Be Down to Luck: Results of a DPN Consultation with Disabled Parents on Access to Information and Services to Support Parenting by Michele Wates). The Handbook will be published in 2004. Contact the DPN for further details.

5 Representation by the Disabled Parents Network to the Department of Health concerning the implementation of *Fair Access to Care Services*

The Department of Health issued guidance concerning the implementation of FACS in the form of questions and answers. Task Force members and the DPN felt that these did not offer enough clarification concerning the treatment of disabled adults' needs for assistance with parenting tasks. The DPN suggested the following:

Q Is the policy guidance wholly directed at adults with care needs?

A Yes. Furthermore FACS focuses on eligibility criteria rather than general service matters such as how councils organise their services for adults. However, in implementing and using the policy guidance, councils will need to be clear how different social services teams and units for all service user groups work together. This is particularly true when disabled adults with parenting responsibilities first approach councils for help. In some cases, there will be no need for children's services to be involved; in others, children will have care needs in their own right. It will be important for children and family teams to have agreed policies and protocols with adult teams on the handling of such cases.

Q The policy guidance does not say very much about adults who are parents and may have parenting needs. How is eligibility for such parents to be determined?

A Many adults who seek social care support are parents of children aged under 18. Assessment of a parent's needs should include their needs for assistance with parenting tasks. 'Parenting roles and responsibilities' fall into those elements of the eligibility framework of paragraph 16 dealing with family and other social

roles and responsibilities. Professionals should be aware that if a disabled parent does not receive the assistance that they need to carry out their parenting role and responsibilities, children's welfare may be adversely affected. However, it is inappropriate to assume that the children of a disabled parent are automatically 'children in need'. A referral to children's services for the assessment of a 'child in need' should not be made without at the same time considering whether the parent's eligibility for assistance with parenting roles and responsibilities has been adequately assessed and responded to under Community Care. If there are concerns about children's welfare that are likely to remain unaddressed even when appropriate specialist services to support adults with their parenting responsibilities are in place, councils should consider their duties under the Children Act and the use of the *Framework for Assessment of Children in Need and their Families*. In exercising these duties, professionals should bear in mind that the provision of services to assist disabled parents to bring up their children is usually the most effective means of promoting the welfare of the children. Where a disabled adult requires assistance with parenting tasks and there are ongoing concerns about a child's welfare, adults' and children's services will need to work closely together, in line with the requirements of both Community Care legislation and children's legislation, to ensure that both sets of needs are addressed.

6 Helping parent support organisations to include disabled parents in the services they offer

The Joseph Rowntree Foundation funded two initiatives to further this aim:

(a) Parentline Plus

Parentline Plus were funded to hold a focus group meeting of disabled parents to help inform the organisation about the experiences of disabled parents and how they could be better addressed by parent

support organisations. Parentline Plus is a charity which offers support to anyone parenting a child – the child’s parents, step-parents, grandparents and foster parents. Parentline Plus runs a freephone helpline (0808 800 2222; textphone 0800 783 6783) and courses for parents, and provides a range of information for parents.

The focus group meeting identified that disabled parents did not currently find parent support organisations, such as Parentline Plus, to be accessible to them. The meeting concluded with some recommendations for Parentline Plus and other such organisations to take forward.

Parent support organisations should:

- undertake Disability Equality training for all staff and volunteers
- monitor and evaluate existing services to find out whether they are inclusive of disabled people
- provide or support the provision of up-to-date information that is appropriate, accessible and includes positive imagery of disabled parents
- ensure that activities such as parenting skills training include specific issues pertinent to disabled parents and their children and are also accessible to disabled parents
- create web links with the DPN, DPP/, Disability Equality in Education and other organisations of disabled people that deal with parenting issues
- develop partnership work with parenting organisations of disabled people, such as the DPN and DPP/, Disability Equality in Education, in lobbying for the rights of disabled parents.

Parentline Plus expressed a wish to develop a strategy to ensure that the organisation’s services are fully inclusive of disabled parents. Further information may be obtained from: Mandy Clifford, Information Services Manager, 0207 284 5500 or mandyc@parentlineplus.org.uk or Gemma Loughran at Parentline Plus: gemma@parentlineplus.org.uk

(b) Parenting Education and Support Forum (PESF)

The Joseph Rowntree Foundation facilitated two meetings between disabled parents and the PESF. The PESF works to improve the quality of education and support services to all parents, and the meetings identified a number of ways in which they could help ensure that such services met the needs of disabled parents. The PESF has set up a special-interest e-mail group for practitioners interested in support for disabled parents. This is a closed group for PESF members. For details of membership contact: dowley@dial.pipex.com or see www.parenting-forum.org.uk

7 Meeting on maternity services and disabled parents

This meeting was held in the Autumn of 2002 and provided an important opportunity for members of the External Working Group on Maternity Services for the NSF for Children, to hear the views of disabled parents. Lynne Hester, a disabled parent, gave a presentation in which she emphasised the importance of accessible free information to disabled parents and parents-to-be, and of making adjustments to services to accommodate parents' particular access needs. She stressed that all staff working in maternity services should have disability equality training. Sabina Chowdry spoke of the particular access needs of deaf parents, and highlighted the importance of making ante-natal and parenting classes accessible to deaf parents and parents-to-be.

Small group discussions included the role of midwives, the integration of voluntary and statutory sectors in providing accessible maternity services, and a good-practice example of improving accessibility of maternity services. It was hoped that the views expressed on the day would influence the maternity module of the NSF for Children and, in furtherance of this aim, the Joseph Rowntree Foundation has commissioned Michele Wates to respond to the NSF's Emerging Findings paper published in the summer of 2003. This response will be posted on the JRF website (www.jrf.org.uk).

Appendix 3: Contact details for the National Centre for Disabled Parents

The National Centre for Disabled Parents is home to DPP/and the DPN.

Both DPP/and the DPN believe that disabled parents have the right to have children and to be supported properly to carry out the important job of being a parent.

Disability, Pregnancy and Parenthood *international* provides a personal and confidential enquiry service and also produces a number of information sheets and a quarterly international journal: Freephone 0800 0184730; Textphone 0800 018 9949; e-mail info@dppi.org.uk; website www.dppi.org.uk

DPN is a nationwide network of disabled parents, their families and allies. They have a contact register and can put disabled parents and would-be parents in touch with each other. They also run a helpline for parents who want moral support from another disabled parent: Telephone 0870 2410450; Admin 020 7263 3088; e-mail information@disabledparentsnetwork.org.uk; website www.disabledparentsnetwork.org.uk

The Centre also offers a resource centre and access to a disabled parent support worker who can give advice to disabled parents regarding rights and entitlement to services.

The postal address for both organisations is: National Centre for Disabled Parents, Unit F9, 89/93 Fonthill Road, London N4 3JH.

