

# **Supporting disabled adults in their parenting role**

**Michele Wates**

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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# 1 Introduction: background to the research

Providing support for parents to help them bring up their children better is at the core of the Government's family policy. However many disabled parents feel that this is still only a pipe dream for them.

(DH/SSI, 2000, p. 1)

A philosophical and practical shift in the approach to working with disabled parents is required. It needs to be underpinned by: A recognition of the right of disabled people, within the bounds of current legislation, to be supported in fulfilling their roles and responsibilities as parents.

(DH/SSI, 2000, p. 2)

This report presents the findings of research commissioned by the Joseph Rowntree Foundation Task Force on Supporting Disabled People in their Parenting Role. Every social services department in England was approached and asked whether they had written policies on providing support to disabled parents, whether they had produced service information for this group of service users and/or whether they planned to produce any such policies or information. The policies and protocols sent were then studied to gain an idea of the main trends in statutory sector service development for disabled parents.

The research was undertaken as part of an ongoing process to develop more timely and appropriate services to support disabled adults in their parenting role. Some other landmarks in this process are outlined below.

### A response to the concerns of disabled parents

In 1999/2000, the Social Services Inspectorate (SSI) looked at what social service departments were doing to support disabled adults in their parenting role. The Inspection report, *A Jigsaw of Services* (DH/SSI, 2000), was based on visits to eight social services departments around the country, and considered what support was currently offered to disabled parents and what could be done to improve services for them. The inspection had been prompted by a meeting in 1997 between a consortium of disabled parents and organisations involved in disability and family rights, and Inspectors from the Social Services Inspectorate. The meeting highlighted a range of concerns.

Disabled parents reported that they found themselves being passed between Adult Community Care services and Children and Family teams providing services to 'children in need'. This resulted in delays or in failure to provide a service. Parents reported that, unless their children were classified as 'children in need', the family had been unable to obtain support, even though the reason parents were seeking services in the first place was to *prevent* their children becoming 'young carers' or 'children in need'.

Parents felt that services offered in many cases undermined them in their parenting, rather than assisting them. Some said that they hesitated to approach social services for fear of attracting labels that would stigmatise them and their families, or even result in their children being removed from home.

### Findings of *A Jigsaw of Services*

The findings in *A Jigsaw of Services* (DH/SSI, 2000) bore out some of the concerns that had been expressed by disabled parents. Overall, the Inspectors found the following:



- Services to disabled parents were patchy and undeveloped, with wide variation in quality from one area to another.
- Adult services teams failed to record routinely that there were children in the family, and children's teams failed to record routinely the presence of a disabled parent.
- Parenting tasks were not generally included in adult Community Care assessments.
- There was very little evidence of a co-ordinated service response to families with dependent children in which one or both parents were disabled.
- Where innovative multi-disciplinary projects did exist, services to disabled parents were frequently their least developed aspect.
- Disabled parents were recognised to be wary of approaching social services.

According to the Inspectors' own analysis of case-work records involving disabled parents, family needs were being met by service provision in only 30 per cent of the cases examined in depth (DH/SSI, 2000, Appendix G, 'Outcomes for users').

The SSI found that only one department of the eight visited had a specific policy laying out disabled adults' entitlement to services in respect of their parenting role. The Inspectors cited the requirement of the 1995 Disability Discrimination Act 'that service providers have to take reasonable steps to change policies, practices or procedures which make it impossible or unreasonably difficult for disabled people to use a service' (DH/SSI, 2000, 1.2, Appendix C).

The Inspection marked a considerable step forward in that it identified problems facing disabled parents as a distinct group of users in accessing services, and highlighted the need for more explicit and better co-ordinated practice in respect of disabled adults with parenting responsibilities.

### Joseph Rowntree Foundation Task Force

Following the publication of *A Jigsaw of Services*, the Joseph Rowntree Foundation set up a Task Force to provide a forum to promote positive change in line with the recommendations of that report. As well as having a number of disabled parents in the group, including representatives from disabled parents' organisations, the Task Force has representation from statutory services (social services, health, education, parent and family support), the voluntary sector, academic researchers and observers from the Department of Health (DH). The Foundation commissioned this research to inform the Task Force and others working to improve services to disabled parents. It was also an opportunity to look at the extent to which joined-up working in support of disabled parents is being developed across agencies.

### The research process

At the end of November 2000, a letter was sent out from one of the Department of Health observers working with the Task Force, to the directors of all social services departments in England, requesting copies of policies, protocols and service user information for disabled parents. The request specified parents with physical and sensory impairments and/or parents with learning disabilities. Documents in relation to parents with mental health and/or drug and alcohol abuse problems were not requested because a complementary research project had been carried out

by the National Institute of Social Work (Kearney *et al.*, 2000) and both sets of data will be used to inform the work of the JRF Task Force.

Following further communications from the researcher, answers were received from 125 out of 151 departments. This final response rate of over 82 per cent is extremely useful in that it provides a comprehensive picture of the current situation throughout England

## **Respondents and contacts**

It was not always clear from the responses which teams or divisions in a given area were seen as being principally concerned with providing services to disabled parents. There were several instances in which separate responses were sent back by different divisions of the same department. This included two cases where personnel from Children's services indicated that their department had no plans to produce a policy, without appearing to know of an existing policy or protocol already sent by the Adults' division! More positively, five departments sent joint responses from Children's and Adults' teams.

Respondents and nominated contacts were twice as likely to work within Adults' than in Children's services. This was true for those departments that did not send policies back as well as for those that did. Contacts were also given in specialist teams for learning disability, sensory impairment and children's disability, in carers' teams and in family centres.

Thirty-one departments (24.8 per cent) sent written policies/protocols. About half of these had been written since the publication of *A Jigsaw of Services*. A further 29 departments (23.2 per cent) indicated that they had plans to produce documents or

that work was already in progress. Sixty-three departments (50.4 per cent) reported that they had no plans at present.

Most of the policies and protocols sent were drafts or else were in the early stages of use and review and, for this reason, even where they are cited and/or quoted, departments are not identified. However, a range of documents that other departments might find useful to consult are listed at the end of this report.

### Parents covered by the policies/protocols

Nine of the policies/protocols stated that they were working with a definition of disabled parents that included parents with physical and sensory impairment and/or learning disabilities. Seven of these also included parents dealing with mental health issues. In several of these cases a comprehensive and inclusive definition such as the following was provided:

Throughout this document any reference to 'disabled/ill parents' should be construed as an inclusive term used for the sake of brevity. 'Disabled/ill parents' embraces all parents who have physical disabilities, chronic and temporary ill health/physical illness, are HIV positive, parents with dependency and addictions, terminal illness, disfigurements, sensory impairments, learning disabilities and/or difficulties relating to personality disorder or mental health.

(Unitary authority interagency policy)

One document dealt with parents with physical and sensory impairments but did not include those with learning disability or mental health problems. Four policies were specific to parents with learning disabilities, three to parents with sensory impairments, two departments indicated relevant sections within 'young carers' policies/protocols and one document was specific to families in

which a parent had HIV/AIDS. The remaining 13 documents did not define which groups of disabled parents were covered.

*A Jigsaw of Services* identified that the particular support needs of disabled parents are more likely to be met when their existence as a group of service users with distinct service entitlements is recognised and promoted by written policies. It is encouraging to note therefore that documents (whether policies or protocols) produced since the publication of *A Jigsaw of Services* were more likely to specify disabled parents in the title.

## **Scope of the documents**

It is worth drawing out the distinction, in some cases made by departments themselves and in other cases implied by the content and scope of documents, between *policies*, or documents that outline the principles upon which practice should be based, and *protocols* that concentrate upon procedures and the allocation of responsibility. Broadly speaking, documents that identified disabled parents as the service focus were more likely to establish a framework of policy principles on which to develop good practice for this particular user group, whilst documents that took inter-service co-operation as their main focus tended to emphasise procedures and the allocation of responsibilities, including who should lead and who should cover the costs of the service.

A quarter of the departments sent dual documents comprising policy and protocol sections. Two documents, both produced within unitary authorities, specified that the document sent was an interagency policy, written with the expectation that individual agencies would write appropriate protocols.

In addition to the policies/protocols, a number of other documents were sent, including flowcharts (seven) to provide an easy-to-follow

diagram of process and responsibility. One department had a very short policy (two sides) but sent with it a table headed 'Objectives/ action/responsibility' which listed very specific actions and set target dates for completion. Three departments sent results of consultations with disabled parents (quoted throughout this report), whilst a fourth sent a questionnaire that was about to be distributed to disabled parents in the area. Letters and notes that came back with the responses, and telephone calls with some of the respondents, were also incorporated into the analysis.

Only three documents were received that were written to inform service users. None of these was specific to disabled parents. One department said that they did have such information but it was not sent.

It seemed that, in a few areas, policies were developed after local disabled parents approached departments and/or following a problematical case or a complaint. There were indications that ideas were spreading from one place to another, notably within the Midlands, the South West region, London and along the South Coast; whether for demographic reasons and/or as a result of historical or personal links. Finally, some departments currently without policies said that receiving the letter and question schedule had given them an extra push to start working on the issues. A number of respondents expressed interest in hearing more about what was happening in other places.

### Summary

In all, just under half of the 125 social services departments that responded had done some work already, were currently doing work, or reported that they had plans to do work in the near future. Less than a quarter of departments have, up to this point,

addressed the needs of disabled parents as a distinct group of service users by producing dedicated policies and/or protocols.

The discovery that a further quarter of departments were actively planning work in this area, and that almost half of the documents sent had been produced since the publication of *A Jigsaw of Services*, gave some cause for encouragement. It was also a good sign that in the course of the research a number of social services departments expressed interest in receiving information about good practice in other places in relation to supporting disabled adults in their parenting role. It was interesting to discover that two-thirds of the named respondents/contacts were based in Adult services.

## **Checklist**

- Where documents were due for review, has this happened and what was found?
- Where local authorities said that they had ‘work in progress’, has this progressed and resulted in the production of policies/protocols?
- Are policies/protocols in use and are all relevant divisions aware of what they say?
- Where no work was planned, is this still the case?

## 2 Legislative background to disabled parents' rights and entitlements

Usually disabled parents were not identified as a relatively discrete group of service users and in only one authority was service provision for them promoted and backed by a specific policy about their rights.

(DH/SSI, 2000, 1.2)

Many staff were unclear, and far from positive ... about parenting needs being part of Community Care.

(DH/SSI, 2000, 4.11)

Many of the policies/protocols revealed a degree of inconsistency between theory and practice in terms of the legislative perspective adopted. There was furthermore a general failure to establish clear procedures for supporting disabled adults to fulfil their roles and responsibilities as parents via Community Care provision, without their children having to be designated as 'children in need' or 'children at risk'. In this chapter, the legislative background to providing services to disabled parents and their families is examined in an attempt to understand why some of these difficulties have arisen.

### **Uncertainty in the policies/protocols as to how legislation applies**

Several of the policies/protocols stated that support to disabled parents should be provided 'within the bounds of current legislation'. What exactly this was seen as meaning (i.e. which legislation is seen to apply when and in what way) often remained less clear.



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## Legislative background to disabled parents' rights and entitlements

Two documents referred only to adult-related legislation and practice guidance. Five referred only to child-related legislation, policy and practice guidance – even though the named contact for four of these policies/protocols was based in Adult services. Three made no reference to legislation or guidance. The remaining 21 documents cited both adult- and child-related legislation or Guidance.

Many of the policies and protocols expressed a supportive intention towards disabled parents and their families. However, they were less specific about legislative and practical routes for supporting disabled adults in their parenting role. Twice as many of the respondents and named contacts across the 125 departments were based in Adults' as in Children's services and a number of the documents indicated that support for disabled parents was regarded as an Adult service issue first and foremost. However, in terms of the actual *content* of the policies and protocols, references to children's legislation, including child protection measures, tended to be more numerous, specific and forceful than those to adults' legislation.

For example, a joint service protocol stated: 'within the current legislative structure the support of disabled/ill parents is primarily based *in community adult Care Service*' (researcher's emphasis). Nonetheless the document contained three times as many references to children's legislation and Guidance as to adults'. Another policy stated that: 'parents should be encouraged to ask for assistance' and, yet, there was a legislative and practical stress throughout on child protection, with continual discussion of the impact of parental illness or disability on the lives of children. In practice, this emphasis might be expected to make parents wary of approaching social services for assistance.

*A Jigsaw of Services* (DH/SSI, 2000) outlines two legislative routes to providing support to disabled adults in their parenting role. 'Best practice', the report suggests, would be via the provision of specialist adult services:

Best practice suggests that a disabled adult's care plan arising from a multi-professional needs-led assessment would include service provision for parenting tasks if appropriate and services would be provided from the relevant sources, including dedicated/skilled workers or agencies.

But children's services might also be used:

An alternative route for disabled parents to gain services to support them in their parenting role is through the child care route. Councils have a responsibility under Part III of the Children Act to provide services to children in need and their families.

(DH/SSI, 2000, 1.9 and 1.10)

The priority of providing a multi-professional, adult care route to service provision for disabled parents is expressed in the stated intentions of many of the policies/protocols examined in this study. In practice, however, applying diverse pieces of legislation and Guidance in relation to families whose situation spans artificial divisions of legislative regulation and service structure is not proving straightforward.

### Community Care

There is an array of Adult and Community Care legislation that upholds disabled adults' entitlements to receive services appropriate to their individual needs. Where the disabled person has parenting responsibilities this will clearly have implications for

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## Legislative background to disabled parents' rights and entitlements

what is required in terms of assistance, adaptations, equipment, housing, access to health care, etc.

The policies/protocols received referred to a wide range of relevant adult disability and carers' legislation and Guidance in terms of its general application to entitlement and service delivery. All of the following requirements were indicated within the group of policies/protocols, in some cases by specific reference to acts of legislation and Guidance issued by the Department of Health, but more often through general references or by inclusion of the relevant legislation and Guidance in lists appended to or included within policies/protocols:

- entitlement to assessment
- making sure that all relevant needs are considered
- making reasonable adjustments to ensure that services are accessible to disabled people
- providing services that are needs-led and suited to individual requirements
- consulting with service users
- access to support and advocacy
- making records available.

Carers' legislation was also cited in relation to providing services to 'young carers' rather than to disabled adults with caring responsibilities for children.

The publication of a *A Jigsaw of Services* in 2000 (DH/SSI, 2000) was consistent with increasing recognition within central

government of the need to address disabled adults' entitlement to assistance in respect of social roles and responsibilities.

*Modernising Social Services* (DH, 1998) specified help to disabled parents to carry out their parenting roles as an essential task of social services for adults. The White Paper *Valuing People* (DH, 2001) has a sub-objective on supporting parents with learning disabilities. Forthcoming Department of Health Guidance on *Fair Access to Care Services* is likely to indicate the need to assess and meet support needs for disabled adults to carry out daily tasks in respect of the family, and to undertake family and social roles and responsibilities including parenting (see below).

### Direct Payments

Very few policies/protocols mentioned the availability of Direct Payments to enable disabled adults to purchase direct personal assistance with parenting tasks and responsibilities. The potential for putting together Direct Payments packages to support disabled adults in their parenting has in fact been extended since many of the policies and protocols were written.

The Community Care (Direct Payments) Act 1996 made it possible for social services departments to provide Direct Payments in lieu of services, to meet assessed needs. The Health and Social Care Act 2001 requires councils to make a Direct Payment to anyone who has been assessed as needing services, who requests one and who is able to manage a Direct Payment, with assistance if necessary.

The Health and Social Care Act will also enable disabled parents to access Direct Payments to purchase services provided under the Children Act 1989, via an amended section 17A. This will facilitate

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## Legislative background to disabled parents' rights and entitlements

Adult and Children's services to put together jointly Direct Payments packages to support parenting and thereby safeguard the welfare of children. Finally, the new strategy for people with learning disabilities, *Valuing People* (DH, 2001), announced the government's intention of encouraging the take-up of Direct Payments by people with learning disabilities/difficulties.

### Valuing People: A New Strategy for Learning Disability for the 21st Century

There is growing recognition in central government policies and priorities of the entitlement of people with learning difficulties to assistance in respect of their family and social roles and responsibilities. Sub-objective 7.3 of the recent government White Paper *Valuing People: A New Strategy for Learning Disability for the 21st Century* is:

Supporting people with learning disabilities in order to help them, wherever possible, ensure their children gain maximum life chance benefits.

(DH, 2001, sub-objective 7.3)

The findings of the SSI inspection underlined that the issue of sustaining support for parents where there are concerns for child welfare is particularly crucial in relation to parents with learning difficulties. For these parents, as for others, research has shown that specialist support and advocacy services are often key to long-term outcomes within families (Booth and Booth, 1998).

These research findings, the SSI's concerns and the accounts of parents with learning difficulties and others presented at a day seminar organised by the Department of Health – reported in DPPi (Disability, Pregnancy and Parenthood international) Journal

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No. 36, October 2001 – all fed into the preparation of the White Paper, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (DH, 2001):

People with learning disabilities can be good parents and provide their children with a good start in life, but may require considerable help to do so. This requires children and adult social services teams to work closely together to develop a common approach. Social services departments have a duty to safeguard the welfare of children, and in some circumstances a parent with learning disabilities will not be able to meet their child's needs. However, we believe this should not be the result of agencies not arranging for appropriate and timely support.

(DH, 2001, 7.40)

The developments outlined above are in line with central government priorities of promoting independence and reducing social exclusion for disabled adults and children, and new legislation in respect of human rights, discussed below.

### **The Human Rights Act 1998**

Three of the more recent documents mentioned the Human Rights Act 1998. A number of provisions in this legislation are relevant to disabled parents including:

- Article 8: The right to respect for private and family life
- Article 12: The right to marry and to found a family
- Article 14: Upholding that the rights and freedoms set forth in the Act shall be secured without discrimination on any ground

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## Legislative background to disabled parents' rights and entitlements

The rights set out in the Human Rights Act 1998 are fully compatible with children's rights and the duty of the State (through local authorities) to safeguard and promote the welfare of children, as set out in the Children Act 1989 and supported by the *Framework for Assessment of Children in Need and their Families* (DH *et al.*, 2000). As the *Framework for Assessment* underlines, two key principles of the Children Act 1989 are that:

- it is in the children's best interests to be brought up in their own families wherever possible
- whilst it is parents' responsibility to bring up their children, they may need assistance from time to time to do so.

### The Children Act 1989

Part III of the Children Act 1989 allows for the provision of services to parents to safeguard the welfare of children as far as possible within their own families. The accompanying Regulations and Guidance make clear that the children of disabled parents should not automatically be identified as 'in need', and that services to the parent can be provided under either adult disabled persons' legislation or the Children Act.

Paragraph 2.5 is particularly relevant for children whose parents may be ill or disabled. This paragraph includes the following:

Children should not necessarily be identified as in need because one or both parents is disabled, although this could of course be a factor. It may be that the provision of services to the parent, either under adult disabled persons legislation or under 17(3) of the Act may safeguard the welfare of the child sufficiently to enable the parent to continue looking after him at home.

The policies/protocols frequently included statements to the effect that adults' personal support needs should be addressed under Community Care legislation whilst children's support needs were covered by children's legislation. The critical issue, remaining unclear in more than half of the policies/protocols, was *whether adult support needs were seen as including parenting tasks and roles*. This issue will be addressed in more detail in Chapter 3, 'Eligibility and assessment'.

The recommendations of the Children Act, also upheld in *A Jigsaw of Services* (DH/SSI, 2000), that the children of disabled parents should not automatically be seen as vulnerable and that services to support parenting may be provided via adults' or children's legislation, does not seem to have translated into consistent practice.

The confusion may arise in part out of the emphasis placed by a number of initiatives emanating from central government in which a rightful concern for children's welfare translates into a shift towards regarding the child as the primary client. It appears that this is having the unintended consequence of marginalising and/or problematising the role of parents. Where this acts as a barrier to parents receiving appropriate and timely support, this clearly does not serve children's best interests.

*A Jigsaw of Services* underlines the need to work in partnership with families:

As a result of research summarised in the Department of Health publication *Child Protection: Messages from Research*, there has been encouragement to refocus children's services nationally. It is intended that services should promote and strengthen family ties and be delivered in partnership with them. Following on from this the Quality Protects Programme aims to transform children's social services. One of its sub-



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objectives (3.4) is 'To ensure that children whose parents have specific needs arising out of disability or health conditions enjoy the same life chances as all other children in the locality'.

(DH/SSI, 2000)

Although the intention is to 'promote and strengthen family ties', the absence of any reference to Adult services suggests that Children's assessment and service provision, rather than support to enable adults with parenting responsibilities to meet their children's needs, remains the primary focus of service provision to families.

### Framework for the Assessment of Children in Need and their Families

This emphasis is also apparent in *Framework for the Assessment of Children in Need and their Families* (DH *et al.*, 2000) which provides policy Guidance for making assessments under the Children Act and, as such, is a major initiative informing policy development, implementation and training within Children's services.

The Framework and the accompanying practice guidance identify three interactive 'domains' to be covered by assessments: the child's developmental needs, family and environmental factors, and parental capacity. In the practice guidance, there is an extensive discussion of the impact of wider factors such as housing, family social integration, employment and income, etc. in relation to disabled *children*. Barriers and difficulties experienced in these areas will have an equally substantial impact on children's welfare where it is the *parent* rather than the *child* who has the impairment but, rather than discussing this and exploring how support needs should be met, discussion of parental impairment in the Framework

is limited to its possible impact upon the individual's parenting capacity and responses.

### Fair Access to Care Services

In respect of disabled adults' needs (described as 'independent of the child's needs'), the *Framework for Assessment* refers social workers to the forthcoming Guidance on the provision of adult Community Care services, *Fair Access to Care Services* (DH, 2002, forthcoming). At the time of writing, this has not yet appeared but it is due for publication at around the same time as this report. It is hoped that it will indicate clearly the need to include family and social roles and responsibilities, which would include parenting, in the eligibility criteria for Community Care services. For the moment (and this it should be remembered has been the background to the preparation of the majority of the policies and protocols considered in this report), there has been no official clarification either of where disabled adults' support needs in respect of parenting sit in relation to the *Framework for the Assessment of Children in Need* nor of how Community Care provision to disabled adults may be used to support them in carrying out parenting tasks and roles.

Some social services personnel identified, in letters and notes that came back with the responses and in the course of informal telephone calls, a degree of difficulty in integrating the recommendations of *A Jigsaw of Services*, that support for disabled parents should be a matter for Community Care legislation first and foremost, with the *Framework for the Assessment of Children in Need*. It was felt that the signposting towards Community Care services to support disabled adults in their parenting role is not made sufficiently clear in the Framework, and that there is no indication, therefore, as to *how* and *at what stage* parental capacity should be assessed in relation to setting

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support measures in place. This was therefore felt to depend largely on the perspective of the individual worker or department concerned.

### Uneven legislative and service drive

There are a number of factors that might be considered to have a bearing on why the application of children's legislation is both clearer and more pressing than Community Care legislation in the policies and protocols.

Whereas the Children Act superseded earlier enactments and Guidance, all legislation in relation to disabled adults continues to apply. Indeed, new legislation and Guidance frequently refer to the requirements of older enactments. This creates a much more diffuse legal picture.

In the policies/protocols submitted, references to Community Care legislation were both less specific and less forceful than those to children's Guidance and legislation. It is understandable that social workers, especially in Children's and Families' teams, are so clearly mindful of the strong imperative around child protection. There are considerable psychological as well as legal and public pressures not to fail in this duty. This awareness is reflected in the strength, clarity and forcefulness of the language used in the policies to describe obligations in this area. For example, a joint service protocol stipulates:

This operational procedure *MUST* be read in conjunction with the Children Act and the Interagency Child Protection Guidelines ... Community Care legislation should also be consulted.

(Emphasis in the original)

A different set of pressures may be uppermost in the minds of policy makers and managers in Adults' services, as they struggle with the dilemma of how to ration service provision most effectively and least unfairly between different groups of adult service users, among whom older people will form by far the largest single group.

Where policies contained specific statements regarding financial limits on services, these tended to be in relation to Community Care services or joint work, rarely in relation to Children's services. The climate of rationing may find itself at odds with the notion of developing preventative support services and services to promote independence. The resultant focus in practice on crisis intervention rather than timely support to families was reflected in the policies/ protocols.

This uneven service drive could potentially be a barrier to providing timely and appropriate support to parents, even increasing the risk of child protection measures being applied inappropriately. This concern was raised in the DH/SSI report *A Jigsaw of Services* which questioned whether the high prevalence of parents (in particular amongst those with learning difficulties) whose children become involved in child protection procedures is either warranted or appropriate. The Inspectors suggested this might result in part from the way services respond, eligibility criteria for Community Care services that omit parenting tasks and responsibilities and reluctance in some areas to recognise disabled adults' additional needs as parents (DH/SSI, 2000, 5.6, 5.12).

### Summary

Both Community Care legislation and the Children Act 1989 may be used to support disabled parents, and indeed *are* being used supportively in some places. However, the absence of explicit

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## Legislative background to disabled parents' rights and entitlements

guidance on how specialist support and other services may be directed towards disabled adults with parenting responsibilities, combined with rationing and resource constraints upon both Adults' and Children's services, has meant that, in many places, disabled parents receive attention from service providers only after problems have arisen in respect of their children. By this stage, parent support may be low on the service agenda compared to child protection considerations. It may be that an unintended consequence of initiatives taken in relation to the Children Act may have been to 'problematise' disabled parents without addressing their support needs.

### Checklist

- Are disabled parents recognised as a distinct group of service users?
- Is service provision for them promoted and backed by a specific policy about their rights and entitlements?
- Is the entitlement of disabled adults to receive a service to support them in their parenting role both recognised in theory and upheld in practice?
- Is there a clear agreement and written policy/protocol across all service divisions specifying how Community Care legislation, in combination with children's legislation where appropriate, is to be used to support disabled parents and families?

# 3 Eligibility and assessment

Ambiguities around the process of assessment – whether it is children’s, adults’ or family needs that are being assessed, and how this impacts on both service allocation and disabled parents’ perceptions of services – emerged as core issues in the study. The focus of this chapter is what the policies/protocols said about establishing eligibility and appropriate assessment in relation to families in which one or both parents are disabled. Assumptions and directives in relation to family and community support are also examined.

## First contact: referral to the appropriate service

A disabled parent may encounter a barrier to receiving support at the very outset of their contact with social services if information is initially passed on to an inappropriate division of the department.

The researcher had the opportunity to observe at first hand how calls and faxes about the research were forwarded by administrative staff to a range of divisions including adults, children and families, family centres and ‘young carers’ services.

It is possible that far-reaching decisions about case allocation may be influenced by administrative workers with little or no social work training: if the person answering the phone assumes that the situation is one of a ‘child in need’ or a ‘young carer’, it may be that Children’s services are informed rather than Adult services.

Administrative workers and receptionists may be the first point of contact between a disabled parent and the social services department. Additional staff training may be required to ensure the most appropriate response.

## Children's or Adults' assessment?

Several of the more recent policies identified the need to co-ordinate the recommendations of *A Jigsaw of Services* (DH/SSI, 2000) with the *Framework for the Assessment of Children in Need and their Families* (DH *et al.*, 2000) that is overarched by the Children Act 1989.

The difficulty identified by *A Jigsaw of Services* and some of the policies/protocols is that, if parenting support needs are not included in eligibility criteria, parents with learning difficulties, with mental health needs, with physical or sensory impairments and Deaf parents are amongst those whose personal support needs, when parenting tasks are left out of the picture, may be seen as failing to reach thresholds for assessment and the allocation of Community Care services. Children's services then become involved because appropriate adult specialist services cannot be accessed. Even then, pressure on resources may mean that the children's needs are seen as falling short of thresholds for receiving a service in many local authorities *unless and until* serious problems are evident, and the child is 'in need of protection'.

Whether the appropriate need is being assessed and addressed, under which legislation, and at what point this happens depends upon the extent to which information is shared between divisions and at what point any cross-referencing between divisions and agencies takes place. The SSI Inspectors found that, in many places, Adult services teams failed to record routinely that there were children in the family whilst Children's services teams failed to record routinely the presence of a disabled parent (DH/SSI, 2000, 1.3). Although the policies/protocols said that information should be shared across divisions, few departments appeared to have established systematic mechanisms for such cross-

referencing at an early stage with a view to preventing problems from arising in families.

### ‘Young carers’

In recent years, there has been a growing emphasis on support to ‘young carers’, encouraged by government initiatives, voluntary sector involvement and legislation. Much less attention has been paid to preventing children from becoming ‘carers’ – in the sense of carrying out inappropriate, or excessive, tasks on behalf of disabled family members – by providing appropriate services to the disabled person. *A Jigsaw of Services* suggested that schemes to support ‘young carers’ may be used to make up for a deficit in service provision, including effective care plans to disabled parents (DH/SSI, 2000, 4.12, 7.15).

The issue of ‘young carers’ was an area of the policies/protocols where stated aims were frequently inconsistent with the measures taken. One of the documents with a ‘young carers’ focus included the statement:

The parents should be supported in their parenting role and services provided so that the young carer is able to benefit from the same life chances as all other children.

(Social services department policy/protocol)

Yet the emphasis throughout was on providing support to ‘young carers’, rather than supporting their parents in their parenting role. Under the terms of this policy, as in many other policies, joint assessment (including assessment of adult needs) *follows on from the identification of a child in need.*

The fact that a ‘young carer’ is being assessed in the first place would in many cases suggest that a service has not been provided



at an early enough stage to prevent problems arising. A barrier to the timely provision of services to support disabled adults in their parenting role, in this social service department as in many others, is that parenting tasks were in many places left out of eligibility criteria for receiving Community Care services.

Disabled parents should be able to access the support they need to allow them to be effective parents, *without* their child having first to be designated a 'child in need' or a 'young carer'. Providing timely and appropriate support to assist disabled adults to fulfil their parenting responsibilities is the best way to safeguard the welfare of children.

It is encouraging that several departments specified that the identification of a 'young carer' (whether or not that young person is already receiving services) should automatically trigger a Community Care assessment for the parent:

If a young carer has been involved a Care Management budget may be used to replace all or some of their support because it is the disabled parent's needs which are being met directly, not the young carer's.

(Social services department policy/protocol)

The measure proposed in this document – that services be given to parents via Community Care budgets – is potentially supportive. But, for parents to qualify for this support, the child must first be seen as a 'young carer'! Over and over again the policies and protocols showed that support to disabled adults in their parenting role would only be mobilised following the identification of a 'child in need' or a 'young carer'.

Disabled parents feel adequate support should be available so youngsters don't have to take on the caring role.

(Social services department consultation with disabled parents)

There are many pressures to continue meeting the urgent and evident needs of young people caught up in inappropriate or excessive caring roles, not least because support has been so forthcoming from the voluntary sector. The danger is that, in the absence of effective preventative parent support measures, the role taken on by 'young carers' and the failure to provide support to disabled parents becomes *reinforced* by service responses.

### Levels of assessment

There are good practical reasons for dividing assessments into simple/initial and full/comprehensive, since the process of assessment is inevitably an intrusive and time-consuming one. Presumably all social services departments have procedural guidelines indicating when a 'simple' or a 'comprehensive' assessment will be carried out; although very few of the policies/protocols provided details of these in relation to disabled adults with parenting responsibilities.

The apparent difficulty is that, if parenting tasks and responsibilities are not included in Community Care eligibility criteria, family support needs are unlikely to score highly on indices of need, and this may mean some adults with parenting responsibilities do not receive an assessment at all, or else not an appropriate level of assessment.

One joint service policy/protocol helpfully set out the criteria for receiving a full assessment. This made it possible to see whether parenting needs might fail to meet the criteria for assessment, just as they fail in many places to meet thresholds for receiving services.

A full/core assessment should be carried out when:

- The needs of the parent are complex.
- There is a risk of significant harm to a child in the family.
- The adult's impairment or illness is stable, but the child's/ children's needs are complex.
- The absence of a full/core assessment is likely to lead to a re-referral.
- Three or more initial assessments have been carried out within the last three months.

(Social services department joint service policy/protocol)

The document quoted above made clear elsewhere that its aim was to be supportive:

Disabled parents have the right to be supported in fulfilling their roles and responsibilities as parents. The needs of children are best met when disabled parents' support needs are acknowledged, assessed, facilitated and regularly reviewed.

The clarity, consistency and organisation of the document all served the realisation of its aims and yet a crucial limitation to the assessment criteria is that the only way to get support where neither the adult's nor the child's needs are considered 'complex' would be to assume that a child may be 'in need' by virtue of having a disabled parent or to make a case for a child being at risk of 'significant harm'.

Children can too easily be defined as 'in need' or 'at risk' without assessment first being made of their parents' entitlement, under Community Care legislation, to support services, including assistance to fulfil parenting roles and responsibilities.

### Eligibility for Community Care services

In those documents that addressed the issue more specifically, some said only that eligibility criteria should be consulted to see if a Community Care service could be provided. Several of the more recent policies specifically stated that eligibility criteria *should* include parenting tasks (a few helpfully itemised the kind of activities this should include) and/or indicated that it might be necessary to re-examine existing criteria.

Among those that raised eligibility criteria as an issue, several documents identified a difficulty in meeting the family support needs of disabled people where the disabled adult's individual support needs do not reach the threshold for Adult services, while the situation of their children is not seen as qualifying for support under children's legislation.

One department reported that they were seeking to address this problem by creating a 'ring-fenced' special budget. The criteria for eligibility would be that: 'The family do not otherwise meet thresholds for the provision of this type of service by either Children's or Adults' services'.

Another department sent a new practice document that it was in the process of piloting. This 'pro forma for an assessment of parenting needs' was designed for use wherever there is a disabled adult with possible support needs in relation to parenting and is intended to be complementary to an adult's or children's needs assessment. In situations where a parent does not meet the threshold for services, the social worker can use the completed form as part of putting forward to management a case for overriding existing eligibility criteria. The adult Independent Living team leads, working jointly with Children's services where appropriate.

Eligibility criteria for Adult Community Care services should include assistance to disabled adults to fulfil parenting responsibilities.

## **Assumptions about family and community support**

*A Jigsaw of Services* identified that assumptions of family support, sometimes made without consultation with families, put existing family lifestyles at risk, occasionally even forcing partners in paid employment to give up work (DH/SSI, 2000, 5.10). Another problem identified by disabled parents' organisations is that, in some cases, where couples have separated following a breakdown of the relationship, departments have approached non-disabled ex-partners to ask what practical help they can provide, rather than addressing the support needs of the disabled single parent. On occasion, this has been done without the disabled person's consent or even prior knowledge (Roberts, 2000).

It was of concern that none of the policies/protocols considered the issue of ex-partners, either in relation to the issue of support or in relation to child custody.

Amongst the nine policies that directly addressed the issue of wider family support, two very different approaches were taken.

Four policies effectively stated that an assessment or service would be provided only if there were no other adult family member (one document did not specify that this person must be an adult) in a position to take on whatever tasks the ill or disabled parent was not in a position to perform. For example:

**An inter agency referral form should be completed where ... there is no other adult within the household or extended family or social network whose involvement can compensate or**

ameliorate the impact of the parents' difficulties and there is likely to be impairment to the child's health or development.  
(Social services department policy)

The appropriateness of another family member taking on such tasks was not discussed in the policy.

Five policies adopted an approach more in line with that advocated by *A Jigsaw of Services* (DH/SSI, 2000). They made a point of saying that social workers should *not* assume that other family members would be in a position to take on tasks. One of these adopted a very clear position, designed to safeguard family lifestyles:

No disabled/ill parent should be obliged to rely upon a family member for inappropriate levels of assistance or for help with inappropriate tasks.

(Interagency policy)

### Summary

Analysis of the policies/protocols suggests that children can too easily be defined as 'in need', or 'at risk', or as 'young carers' without assessment being made of their parents' entitlement, under Community Care legislation, to support services, including assistance to fulfil parenting roles and responsibilities. A recurrent difficulty thrown up by the policies/protocols is that, where parenting tasks are left out of eligibility criteria for Community Care services, disabled parents will either not reach the threshold for receiving Community Care services or will not receive the additional support needed to meet *parenting* as well as personal needs. At the same time, children may not be eligible for assessment unless and until their problems are perceived as

sufficiently serious. The assumption that family members will meet shortfalls in service provision may have the unintended effect of forcing partners out of paid employment or young people into inappropriate roles and/or excessive tasks.

## **Checklist**

- Are parenting tasks and responsibilities included in the department's eligibility criteria and covered in assessment for Adult Community Care services?
- Is the meeting of needs associated with parenting responsibilities regarded as a priority for access to assessment and service allocation?
- Do administrative workers and receptionists receive specific training on how to respond to enquiries from disabled parents?
- Do Adult services teams record routinely that there are children in the family?
- Do Children's services teams record routinely the presence of a disabled parent?
- Are mechanisms in place that will ensure timely and effective cross-referencing between divisions in relation to disabled adults with parenting responsibilities in good time to prevent problems arising?
- Are parenting tasks and responsibilities included in the department's eligibility criteria and covered in assessment procedures for Adult Community Care services?

## Supporting disabled adults in their parenting role

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- Can disabled adults access the parenting support they need without their children first having to be designated as 'children in need' or 'young carers'?
- Do policies/protocols make it clear that no parent should be obliged to rely upon a family member for inappropriate levels of assistance or for help with inappropriate tasks?



# 4 Supportive intentions – supportive practice?

*A Jigsaw of Services* (DH/SSI, 2000) revealed that many disabled parents were reluctant to approach social services departments, fearing that social workers would decide they were not good enough parents and remove their children from home. The Inspectors did not consider that parents' fears were borne out by what they found happened in practice in the eight local authorities visited, although they did express their concern about what they felt to be the unjustifiably high numbers of parents with learning difficulties whose children were the subject of child protection measures.

It is important to examine what might make parents hesitate, or even decline, to approach their local social services department for the support they need. The aim of this chapter is to examine some of the elements in existing practice that might deter parents or else be experienced as barriers to receiving support by parents involved with social services departments.

## **'Child in need' as the only route to support**

Many of the documents appeared to be underpinned by the assumption that the children of disabled parents, or at least of any disabled parents who require support services, should automatically be regarded as vulnerable children.

This was evident in all three of the policies submitted relating to parents with sensory impairments. Although each of the policies identified a different focus in the title (*Hearing Children with Deaf Parents*, *People with Sensory Impairments* and *Deaf Children and their Families*, respectively), each of them was written from the perspective of the child as primary client, with no explicit mention

of using Community Care provision to support Deaf or sensory impaired adults in their parenting role.

In several of the policies/protocols which clearly expressed a supportive intention to disabled parents and did in fact mention Community Care provision, it was made clear that there was not an automatic assumption of vulnerability. Nonetheless, in a number of them, it appeared that the only way for a disabled parent to access support would be via Children's services. Adult assessment might follow, or even take place at the same time, but the perceived needs of the child were key to triggering assessment.

In only nine out of the 31 policies/protocols received was it clearly possible for a disabled parent to access support without their child first being designated a 'child in need' and undergoing a children's assessment.

It could be argued that a focus on a child as being 'in need' within the terms of the Children Act is about prevention in order to avoid a situation where child protection procedures come into play. However, if a non-disabled parent in the same situation (but without the needs relating to impairment) is able to access information and resources through mainstream and community sources to support their parenting, without having to go through the process of having their child assessed as a 'child in need' and without their parenting capacity being subject to scrutiny, then, disabled parents might argue, they shouldn't have to either. Seeking to develop a 'level playing-field' is key to providing services that parents experience as non-discriminatory and non-stigmatising.

Services are less likely to be experienced by disabled parents as stigmatising if it is made clear that being a disabled parent does not *mean that a child is automatically "in need"* and does not in itself constitute a child protection issue.

## How parent support falls from the agenda

At the point when serious family difficulties arise, issues such as confidentiality, service co-ordination and continuity of relationship with key workers become particularly crucial. However, analysis of the policies/protocols suggests that it is precisely at this point that dialogue with parents in relation to such issues is likely to become a secondary consideration and may fall from the service agenda altogether.

A noteworthy exception to this was the interagency policy concerned exclusively with parents who are HIV positive or who have AIDS. This document demonstrated a clear awareness of the complex social contexts within which services are provided and stressed the importance to parents themselves of informed consent, maintaining confidentiality wherever possible and providing services in a manner that does not have the unintended effect of stigmatising service users. It was significant that more attention was given in this policy to the issue of how parents *perceive* services than in any other.

A number of policies that expressed an intention to be supportive to disabled parents nonetheless failed to address what should happen in terms of the ongoing involvement of Adult services where there are child protection concerns. Almost all of the policies/protocols that mentioned the issue stated that responsibility in such cases would transfer from Adult services (or joint working across Adult and Children's services) to Children's services.

Of the 31 policies, 12 advocated the use of key workers to enable a more co-ordinated and appropriate service response. However, the majority of policies that specified circumstances under which

responsibility would transfer from Adults' to Children's services did not consider the issue of continuity in the event of such a transfer.

A document with the stated aim to be supportive to parents with learning difficulties stipulated that, in situations where there are concerns for a child's welfare, the Children's team worker 'must' lead the case conference, whilst the Adult worker 'may' be only invited to attend. Under such arrangements, a parent could find that they moved rapidly from having a key worker based in Adult services to a situation where their perspective as parent is no longer represented in discussions of the family's future.

Few policies/protocols covered potential shifts in the legal status of parents and sensitivities around potential disruption in parents' relationships with service providers. In practice, such considerations are likely to have considerable impact upon the relationship between social services and families, and this may have negative implications for parents, children and service providers.

A number of departments indicated that standard procedures could be waived in child protection situations:

In situations of high risk or complexity, where the children are subject to a core assessment then a formal planning meeting will be convened to which all professionals will be invited along with the family. The purpose of this meeting will be to draw up and agree a plan of assistance to the family as well as a review procedure. *The exception to this* will be when the threshold for child protection is crossed and those procedures then apply.

(Social services department protocol for work with parents with learning difficulties, emphasis added)

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## Supportive intentions – supportive practice?

Where child protection is a concern, normal procedures in relation to confidentiality, consultation and the routine involvement of adult services are not necessarily seen as applying. This must be a cause for concern when considered alongside the findings of the SSI Inspectors, reported in *A Jigsaw of Services*, that child protection investigations do not always appear to be used appropriately (DH/SSI, 2000, Appendix G, 'Outcomes for users').

Of the policies received, very few set out specific steps to address the issue of support to parents where child protection procedures are being followed and/or where children have been removed from home.

When child protection procedures are instituted, departments should ensure that disabled parents continue to receive specialist support and have access to such advocacy as they require.

A number of the joint service protocols discussed procedural issues around transfer of responsibility in detail, but without considering the implications for parents of such a transfer. It is therefore worth quoting from a policy that did address this:

There are occasions when delayed support results in crisis intervention, sometimes resulting in child protection situations. If the child is removed it may be appropriate to maintain or change the type of support to the parent for a period of time. Complete withdrawal without alternative support should not be considered.

(Social services department policy on supporting parents with disabilities)

This policy goes on to mention the importance of access to counselling and advocacy services for parents.

### Parents with learning difficulties

Concern was expressed in the SSI report *A Jigsaw of Services* as to whether the high prevalence of parents (in particular amongst those with learning difficulties) whose children become involved in child protection procedures is either warranted or appropriate. The Inspectors suggested this might result in part from the way services respond, eligibility criteria for Community Care services that omit parenting tasks and responsibilities, and reluctance in some areas to recognise disabled adults' additional needs as parents (DH/SSI, 2000, 5.6, 5.12).

This tendency was borne out by the marked emphasis given to child protection issues in three of the four policies/protocols dealing exclusively with services to parents with learning difficulties. However, the fourth document, an interagency protocol, deliberately gave more emphasis to the role of specialist Adult services.

The protocol, which has been prepared by the Area Child Protection Committee 'following response to a retrospective audit ... on a particular case', was the only one of the 31 policies/protocols to specify that Adult services should continue to maintain the lead even where there were concerns for the welfare of children:

**Where both Adult & Child Care Services are involved the adult care manager will maintain care management responsibilities and will ensure that all the childcare issues are fully incorporated into the care plans.**

Specifying that Adult services should maintain lead responsibility even where there are concerns for children's welfare was felt by the writers of the protocol to ensure continuity of support and the

ongoing involvement of specialist Adult workers in addition to specialist Children’s workers.

The White Paper, *Valuing People* (DH, 2001), which was mentioned in Chapter 2 of this report, emphasises the need for agencies to arrange timely and appropriate support to parents to *prevent* children being removed from their parents’ care. This need for a preventative approach was expressed particularly clearly in one interagency protocol in relation to parents with learning difficulties:

This protocol is written in response to a burgeoning number of parents with learning disabilities whose first contact may be with Social Services Child Protection Services where their ability to parent safely is already in question. Some of these parents have struggled without help for years to cope with the responsibilities of parenthood. Help and support at the earliest opportunity might have made the difference between successful parenting and the child being significantly harmed ... this protocol seeks to address this issue at the earliest opportunity.

(Interagency protocol)

Providing specialist support via Community Care *before problems arise* and ensuring that this continues, even where there are problems, is key to successful long-term outcomes for parents and their children.

## Disabled parents’ perceptions of services

If statutory agencies are involved, disabled people feel like they are living in a goldfish bowl and everything they do is scrutinised, assessed and criticised.

(Social services department consultation with disabled parents)

Parents see social services as a body for neglected children and cannot see what relationship it may have to supporting them. They feel specialist workers' views are not always accepted as strongly as child protection views.

(Social services department consultation with disabled parents)

Social services departments' consultations with disabled parents highlighted that the concerns uppermost in the minds of disabled parents as they approach social services departments – anxieties that social services will be critical of their parenting, concerns about ongoing scrutiny, fear of stigmatising labels being applied to their families, etc. – may be quite different from the concerns uppermost in the minds of service providers as they prepare policies or protocols.

One policy stated that, in any case where there have been childcare concerns, 'routine checks' may continue *even after the case is closed to children's services*, 'so long as the adult case remains open' (researcher's italics). This is an example of how parents' support needs become tied to perceived risks to their children and how, when disabled parents say they feel under constant scrutiny, this may be literally true.

Disabled parents may be deterred from seeking potentially valuable support by a perception that social services departments are predominantly concerned with child protection issues and have nothing to offer them or will intervene in ways that will undermine, rather than support, their parenting role.

Anxieties were expressed about potentially conflicting roles held by social services departments in relation to parents and there was concern about the possibility that what appeared to be temporary relief offered to families experiencing difficulties might result in



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## Supportive intentions – supportive practice?

children being taken into the Looked After system on a longer-term basis:

Disabled parents disliked the term 'Respite'. Where support/break is needed both should be promoted positively together. Foster care should be provided as support, not receiving into care.

(Social services department consultation with disabled parents)

There is a danger that parental reservations about approaching social services departments will increase with proposed legislation designed to speed up and 'simplify' the permanent placement of children who enter the Looked After system (DH, 2000). There was no mention within the policies and protocols of the fact that different divisions of social services departments have responsibility both for supporting families in difficulty and for placing children for long-term fostering and adoption. Nor was there any discussion of the need to reassure parents in respect of the liaison between these divisions.

## Developing services in line with the social model of disability

Disabled parents are made to feel that they are a problem and that the support they are requesting is unreasonable.

(Social services department consultation with disabled parents)

Much service provision with a bearing on the lives of disabled people and their families works from the assumption that disability is a physical, mental, sensory or cognitive characteristic of the individual, which to a greater or lesser extent causes problems for them and for those who live with them.

## Supporting disabled adults in their parenting role

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Work that is consistent with the social model of disability, on the other hand, defines disability primarily as a social experience in which factors such as attitudes towards disabled parents and the way in which services are planned and delivered may have just as much or even more of an impact on the lives of disabled people and their families than the presence of impairment (Swain *et al.*, 1993).

Services that follow the social model of disability may be found more acceptable by disabled parents, since the focus is the removal of barriers to successful parenting, rather than identifying the parents themselves as the problem.

Seven documents mentioned the social model. One policy explained that:

The social model of disability is about civil and human rights and responsibilities and removing the barriers to independence and equal opportunities faced by disabled people.

## Involving disabled parents in developing services

Having identified disabled parents as a distinctive group of service users, it is of key importance, and consistent with the social model of disability, that services are developed and evaluated in collaboration with parents. Even so, only three out of the six policies/protocols that mentioned the social model gave any indication of having involved disabled parents in forming their policy. Interestingly, it was much more common to find that disabled parents had been consulted or involved in the preparation of policies that focused on disabled parents as a distinct group of service users than in those relating to joint service arrangements.

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## Supportive intentions – supportive practice?

Involving disabled parents and their national and regional organisations in policy development and service monitoring is essential if services are to be developed which disabled parents find welcoming and supportive. It is important to include parents with a range of impairments and experiences and from local minority ethnic communities, and for involvement to begin at the outset and be ongoing.

Several departments indicated a growing awareness of the need to consult with and involve disabled parents in developing services. Examples given in the responses included:

- involving representatives from local and national disabled parents' organisations at each stage of policy formulation
- planning a widespread consultation of disabled parents (though it was less than ideal that this followed the drafting of the policy)
- inviting a representative from a local disabled parents' organisation to make a presentation at the launch of a policy-making initiative
- conducting a survey of disabled parents' views on a range of services (though few of the specific points raised by parents seemed to have been addressed in the resulting policy).

## Summary

Although social services departments are aware that disabled adults are wary of approaching social services for support with parenting, they appeared to be taking few measures to allay these fears. An emphasis on children's legislation and on child protection, and the comparatively small amount of attention given to Community Care legislation and to providing specialist adult support mean that help for disabled adults in their parenting role

may all too easily slip down the agenda where there are concerns for children's welfare. Ensuring the involvement of specialist adult workers *throughout* the contact with the family, including in cases where there are seen to be child protection concerns, gives the best chance of ensuring continuity of support to the parent and a better relationship between parents and social services.

### Checklist

- Does the policy/protocol make it clear that the children of disabled parents are not automatically regarded as vulnerable?
- Is it possible for a disabled adult to access support for parenting without having to question whether there is a 'child in need'?
- In cases where there are child protection concerns, how is the ongoing involvement of both Children's and Adult specialist workers co-ordinated?
- Do all parents have access to advocacy services?
- Have disabled parents' perceptions of social services been evaluated?
- Are cases in which child protection measures are taken monitored to make sure that this is the most appropriate response?
- What steps have been taken to allay disabled parents' fears in relation to approaching social services departments and to ensure that services are welcoming?
- Are disabled parents involved in service development, monitoring and evaluation?

# 5 Service provision

## Responses to assessed needs

Whilst the question of resource limits is raised explicitly in just over a third of policies/protocols, consideration of whether the services currently available are right for the task is rare. However, issues raised throughout this report, outlining inconsistencies between stated aims and measures taken on the one hand, and the gap between providers' and users' perceptions of services on the other, suggest that the suitability of available services is in practice a key issue.

Several policies specified that assessments would identify needs and that, even where these could not be met 'within the limits of available resources', they must be recorded.

There are two distinct questions here:

- 1 whether assessed needs can be met *within available financial resources*
- 2 whether assessed needs can be met *by existing services*.

The recording of unmet needs is cold comfort for parents unable to get hold of services but it can be argued that it has a function in terms of service development.

If the support needs of disabled parents are consistently unmet, it indicates the necessity to develop services more appropriate to the requirements of this user group.

### Balancing budgetary constraints and needs-led service provision

Many of the policies/protocols (including the one quoted below) said that their intention was to be needs-led rather than service-led. The way budgets are organised, however, can create a push to provide a certain type of service *in order to transfer funding responsibility* onto another service division or agency.

In a number of policies and protocols, the financial arrangements were left vague and/or were so complex that it is easy to imagine that they could become a source of dispute. The bottom line of even long and apparently comprehensive procedural protocols may be that a great deal (including finance) was left to negotiation on a case-by-case basis:

Where services are to be purchased it may be appropriate to jointly commission in which case the budget holders within each Division must agree the apportionment of costs on a case by case basis in line with eligibility criteria.

(Joint service protocol)

There is nothing in such arrangements to reassure an anxious family facing urgent difficulties that they can expect prompt agreement on appropriate service delivery, especially where parenting tasks are not actually specified in the eligibility criteria for adult services.

Financial and practical arrangements should be clearly established with the aim of providing a prompt and appropriate service response to disabled parents that is needs-led rather than dictated by existing service structures and/or budgetary considerations.

According to the above protocol, a Children and Families budget would cover the cost of sending a small child to full-time day nursery, whilst the cost of help in the home would be met by Adult services:

Where social care services for a family are as a result of the disability or parent's mental illness, then those will be purchased by Services for Adults. The provision of services outside the family home if required to meet the child's needs will be purchased or provided by services for Children and Families.

(Joint service protocol)

What can happen under such arrangements is that the needs and wishes of family members become secondary to financial wrangling between service divisions over which of them should pay.

One document discussed this candidly:

It is often suggested that another team should be involved because another budget would be more correct. Budget holders under pressure often look for more suitable purchasers.

(Social services department joint service protocol)

A good example of this would be the perennially vexed issue of which social services division should cover the cost of assisting disabled parents to get their children to school, or indeed whether it is the responsibility of the education service. As arguments about who should pay pass to and fro, vital considerations about what arrangements actually make the most sense for the parent and child(ren) concerned, and how to build in flexibility as needs fluctuate and circumstances change may be lost from sight.

Further constraints, often linked in with budgetary considerations, stemmed from the nature of the assistance available. Results of three consultations with disabled parents suggested that parents have difficulties with the fact that in many local authorities care workers and agency staff are not permitted to help with both housework *and* childcare tasks, that home-based staff put in by Children's services have no brief or training in relation to supporting parenting, that there is a constant turnover of staff, that families do not know who will appear from one day to the next nor at what time. Having passed through all the hoops and managed to get hold of a service, the way in which the service is provided may be incompatible with the demands and contingencies of family life.

The issue of the suitability of existing services, though so crucial to parents, was seen as lying outside the scope of many of the joint service protocols and rarely received attention in policy documents. In places where disabled parents had been proactive in getting departments to draw up policies and had played a central role in their development, noticeably more attention was given to the characteristics of service provision, as in this policy, that was accompanied by a protocol:

The key to effective provision of services for disabled parents is flexibility to allow the parent to receive support in a way that is most beneficial to them and their child, enabling them to retain control of their child's upbringing. There should be the following possibilities:

- Support provided to parents who wish to undertake most parenting tasks themselves, possibly using Direct Payments/the Independent Living Scheme.
- Support involving some parenting tasks undertaken by an assistant, under the direction of the parent.



- Support that enables parents to have adequate rest.
- Sufficient flexibility to enable parents to vary their involvement in parenting tasks according to variations in their health and ability at different times.

Only two policies (both written within the last year) actively promoted the use of Direct Payments, specifying that arrangements should be provided as part of Community Care services as a means of maximising the flexibility of services in the recruiting and working relationship with supporting personnel. Others made only passing and/or indirect references to Direct Payments and most made no mention of them.

Research shows that Direct Payments improve the quality of life of disabled people by allowing choice, control and flexibility and result in high levels of user satisfaction (Dawson, 2000; Hasler *et al.*, 1999; Zarb and Nadash, 1995). (See Chapter 2 for information on the current legislative framework for Direct Payments as regards disabled parents.)

## **Review of services**

As with the recording of unmet need, service review has two distinct aspects; individual case review on the one hand and review of the effectiveness of services on the other. Most of the policies and protocols specified the procedures for individual case review. Timetables appeared for the most part to be those established for the department's work in general, broadly in line with national standards and Guidance. However, a small number of the policies examined the issue of review more specifically in relation to the needs of disabled parents, stressing that disabled people's needs and children's lives (and therefore parenting needs) change, in ways that can be foreseen and in ways that cannot.

The timescale for review should therefore be set in response to the particular circumstances surrounding the disabled parent's needs, the changing needs of the child and the complexity and size of the package being provided.

There should always be the flexibility for a case to be re-reviewed at any time or re-opened speedily if they have been closed.

(Social services department combined policy/protocol)

In many documents, arrangements were built in for the review of the service arrangements set in place by the protocols/policies. Often a time-frame was set for review. A valuable follow-through on this research would be to ask departments whether these reviews had been completed and if so what had been found to be working well and where there were issues/challenges still to be resolved. Reviews of services should also look at take-up and response of disabled parents to the available services.

### Charging

From disabled parents' point of view there is a further substantial problem in that Community Care services are liable to charges whilst Children's services are not. The critical issue of charges made to parents for services is addressed only in a couple of the documents. This is an area where, given the impact on parents and service providers alike, more discussion might have been expected and would certainly have been useful.

A joint service protocol, specific to disabled parents, included the stipulation: 'Charges should not be made for services which are provided to assist in parenting activity'. It is not clear whether this would include services provided via Community Care assessment or just those made via Children's services. Perhaps the lack of definition on this point was not altogether unintended, for a note

was added to the policy to the effect that transferring money from one part of social services to another in a flexible arrangement was an outstanding question within the department.

The pro forma developed by one department for use alongside adults' and children's assessments specified that: 'charges should be waived for child related adult needs'.

The possibility of innovative arrangements across divisions and even agencies is discussed in the final chapter of this report.

## **Parents from minority ethnic communities**

Another area in which the declaration of supportive intent was rare, and the description of concrete supportive measures rarer still, is that of practice in relation to parents and families from minority ethnic communities.

Nine out of 31 policies mentioned this issue. However, only three indicated specific measures to be taken: one department had included questions on ethnic origin in a forthcoming local survey of disabled parents' experience as service users (see documents listed at the end of this report); a second included advice on challenging discrimination and harassment; and a third referred to language interpretation services. The issue of language interpretation may be covered by other social services policies but this was the only policy/protocol (out of the total of 31 received) to indicate this.

Due regard to the Race Relations (Amendment) Act 1999 accompanied by careful monitoring of services to disabled parents from ethnic minorities should lead to the adoption of *specific and targeted measures*, aimed at providing culturally sensitive and appropriate assessments and service responses.

### Summary

Comparatively little attention was given in joint service protocols (though rather more in policies specific to meeting the needs of disabled parents) to the accessibility and suitability of available services. Although a lot of attention was given to the apportionment of costs between divisions, arrangements for cost *sharing* received less attention. Very few policies/protocols addressed the issue of whether charges should be waived in respect of Community Care services to support disabled adults with their parenting responsibilities.

### Checklist

- Are clear arrangements in place across divisions of social services departments and between agencies for pooling budgets and sharing costs?
- Might charging policies for parenting tasks be waived in line with a preventative approach to family support, regardless of which budget the support is funded from?
- Are Direct Payments promoted to meet parenting support needs? Since this is possible both under Community Care legislation and under the Children Act 1989, are there arrangements for joint Direct Payments packages (which might also include health services) to be made where appropriate?
- Are disabled parents consulted on their access to and experience of services intended to support them in their parenting role?

- Are specific and targeted measures in place to ensure services are accessed by and appropriate to black and minority ethnic disabled parents?

# 6 Developing supportive strategies

Do your organisational structure and management arrangements facilitate efficient delivery of services to support disabled parents?

(DH/SSI, 2000, 2.6)

It has been shown that the way that services are organised and paid for often skews provision towards a 'child as client' perspective rather than supporting disabled adults in their parenting role. Policies generally operate from within existing styles of provision, without tackling the considerable limits these can place on arranging more timely and effective support to disabled parents and their families.

It was encouraging to see examples, albeit from a small number of innovative departments, that are looking to set up service structures, financial protocols and ways of working that are more enabling of disabled adults in their parenting role. Such new approaches were in several cases found to be prompted and driven forward by disabled parents themselves.

## Providing service information to disabled parents

Most disabled parents feel more comfortable asking the voluntary sector for support, advice and information as they feel there will be less intrusion and criticism.

(SSD consultation with disabled parents)

*A Jigsaw of Services* found that disabled parents known to other agencies sometimes declined to be referred to social services and were fearful of social work intervention (DH/SSI, 2000, 1.18–19).

Parents can only benefit from services if they know about them and trust their supportive intention. Providing service information that is clear, consistent and in a range of accessible and appropriate formats is essential and will do much to reassure parents. Voluntary sector organisations and community-based projects have a role to play in helping parents to access information and services.

The policies examined in this research showed that social services departments are aware of parents' reluctance to approach social services, but there was generally little evidence that departments were designing services in a way that would lessen anxieties and/or increase access. There were exceptions to this, as in the policy quoted in the box below.

The availability of services for disabled parents should be publicised in places parents are likely to visit, for example, baby clinics, GP surgeries, schools, playgroups, libraries, as well as places disabled people are likely to visit.

(Social services department policy)

No examples of information written specifically for disabled parents were received in this research although one department said that they had such information and six others said that they had plans to produce such information.

## Promoting Direct Payments

Promoting the use of Direct Payments to disabled adults to purchase assistance to fulfil their parenting roles and responsibilities is clearly an area that warrants further and proactive development, given the high levels of satisfaction recorded by disabled adults who use Direct Payments to purchase

personal assistance, and the potential of Direct Payments as a means of securing more flexible, needs-led and appropriate support.

Two of the 31 policies actively promoted the availability and use of Direct Payments for disabled adults to purchase assistance to fulfil parenting roles and responsibilities.

As stated in Chapter 2 of this report, the Community Care (Direct Payments) Act 1996 made it possible for social services departments to provide Direct Payments in lieu of services, to meet assessed needs. The Health and Social Care Act 2001 (due to come into force in 2002) will require councils to make a Direct Payment to anyone who has been assessed as needing services, who requests one and who is able to manage a Direct Payment, with assistance if necessary. The Act will also allow disabled parents to access Direct Payments to purchase services provided under the Children Act 1989, via an amended section 17A. This will enable both Adults' and Children's services to put together a Direct Payments package to support parenting and thereby safeguard the welfare of children.

### Working across divisions

Where divisions are separate and working to different legislative requirements, structures and budgets, the danger is that they relate to various client groups rather than to *families*, and that disputes may arise across divisions, delaying service provision and causing unwarranted anxiety to parents. Some departments found the following innovative ways to address these problems:

- Appointing a specialist worker, dedicated to supporting disabled parents, to liaise between Adults' and Children's divisions.



- Specifying that two key workers should be involved on occasions where there may be a potential role conflict for a single key worker.
- Specifying that Adult services should continue to be in charge even where there are concerns for the welfare of children.
- One department had set up a working group to link divisions – to meet quarterly, alternate venues and produce regular bulletins – to include three members from Adults’ services (specialising in mental health, physical disability and learning disability) and two from Children’s services (specialising in mental health and disability). However, it was a pity that membership of the group did not appear to include parents.
- Overall, 12 departments advocated the use of a key worker to enable a more co-ordinated service response.

Because the needs of disabled parents and their families do not fit neatly into current service structures, local authorities need to develop new ways of working that promote flexibility and are determined by service users’ needs rather than by organisational structures.

## Financing joint working

How to jointly finance services to disabled parents and their children across service divisions in a manner that is prompt, supportive and holistic is perhaps one of the major challenges identified in this study.

Various measures to combine resources from Adults’ and Children’s services are set out within the policies. These include a pooled budget and a pre-set allocation of costs in cases involving both services. Detailed descriptions of procedures for pooling

budgets were rare, so it is worth giving an example of where this has been done clearly and concisely.

The following process is designed to formalise joint responsibilities and sharing of costs whilst ensuring that there is sufficient flexibility to meet identified needs.

Finance administration of joint packages between adult assessments and the children's division will be undertaken by Adult Services.

Budgets will be identified for:

- Care packages provided by private and voluntary agencies
- Care packages provided by cost and volume contract providers
- Care packages provided by the Federation of Voluntary Care Providers
- Care packages funded under Direct Payments arrangements

Allocated finances will be identified at the beginning of each financial year and placed in a single budget to be administered by Adult Division applying a 70 per cent Adults 30 per cent Children split.

(Social services department joint service policy/protocol)

In the three other instances where apportionment of funds was discussed, a 50/50 split was proposed.

Pooled budgets may ensure a supply of money available for supportive initiatives to be taken quickly, without extensive financial negotiation. Permanent arrangements are needed, rather than short-term or one-off measures.

### Partnership working with other agencies

A philosophical and practical shift in the approach to working with disabled parents is required. It needs to be underpinned by ... protocols, practical arrangements and strategies to improve inter divisional/corporate/interagency work at an individual and strategic level.

(DH/SSI, 2000)

Family life crosses the boundaries of a range of agencies, including maternity services, pre-school education, social services, schools, primary care teams, mental health, youth service, leisure and housing. Disabled parents are likely to come into contact with a wide range of service providers in both the statutory and voluntary sectors.

The need to advance partnership working with other agencies was therefore seen by several local authorities as particularly crucial to meeting the needs of disabled parents. Even where there were no plans specifically to develop an interagency approach, several policies mentioned other agencies, on the grounds that social services departments might need to refer parents to other agencies or vice versa.

Disabled parents may be very wary of approaching social services departments, fearing that their parenting will be criticised and/or undermined. Collaboration between statutory agencies, voluntary sector organisations and community-based projects may be a more successful way of reaching disabled parents.

Examples from the policies of interesting ideas and supportive strategies are outlined in the rest of this section.

### Interagency protocols

In one area, a citywide protocol on parents with learning disabilities had been initiated by the Area Child Protection Committee, for use by the health authority, unitary city services, community services, NHS trusts and hospitals. The aim was to avoid crisis-driven involvement of social services by providing timely, appropriate and co-ordinated support early on, and to do this by involving GPs, health visitors, parent educators and the specialist Learning Disability service. It was intended that the presence of a parent or prospective parent with learning disabilities would trigger a core assessment, led by Adult services, to determine appropriate Community Care support.

### Interagency approach to assessment

All the agencies have a separate assessment process, which means that, each time a new agency is involved, another assessment has to be completed.

(Social services department consultation with disabled parents)

One policy outlined an interagency approach to the assessment process that might help to overcome the problem outlined above by a disabled parent:

... at the start of an assessment a planning meeting should take place between a social worker/care manager from each service, the family and relevant professionals from other

agencies who might be asked to contribute to the assessment process.

The same policy helpfully provided a list of 'support tasks to enable the parenting role' that potentially spanned the remit of different agencies, for example: parenting within the home, taking a child to school, attending school events, involvement in children's play, using sports centres, attendance at hospital appointments, etc.

### Interagency working groups

Working groups with representation from a range of agencies had produced three of the 31 policies (one concerned with HIV, one concerned with learning difficulties and one using a definition of disabled parents that included physical and sensory impairments, illness, learning difficulties and mental health). All the agencies were within unitary authorities.

All three had drafted documents to be used as policy frameworks, on the basis that different agencies could develop and share compatible protocols.

Forward-looking service providers are considering how a joined-up approach to meeting the needs of disabled parents may be achieved in practice.

### Appointing a co-ordinator for interagency work

In one unitary authority (where there was an interagency working group), a two-year appointment had been made with the specific intention of co-ordinating this interagency work and the development of compatible protocols.

### Joint training across agencies

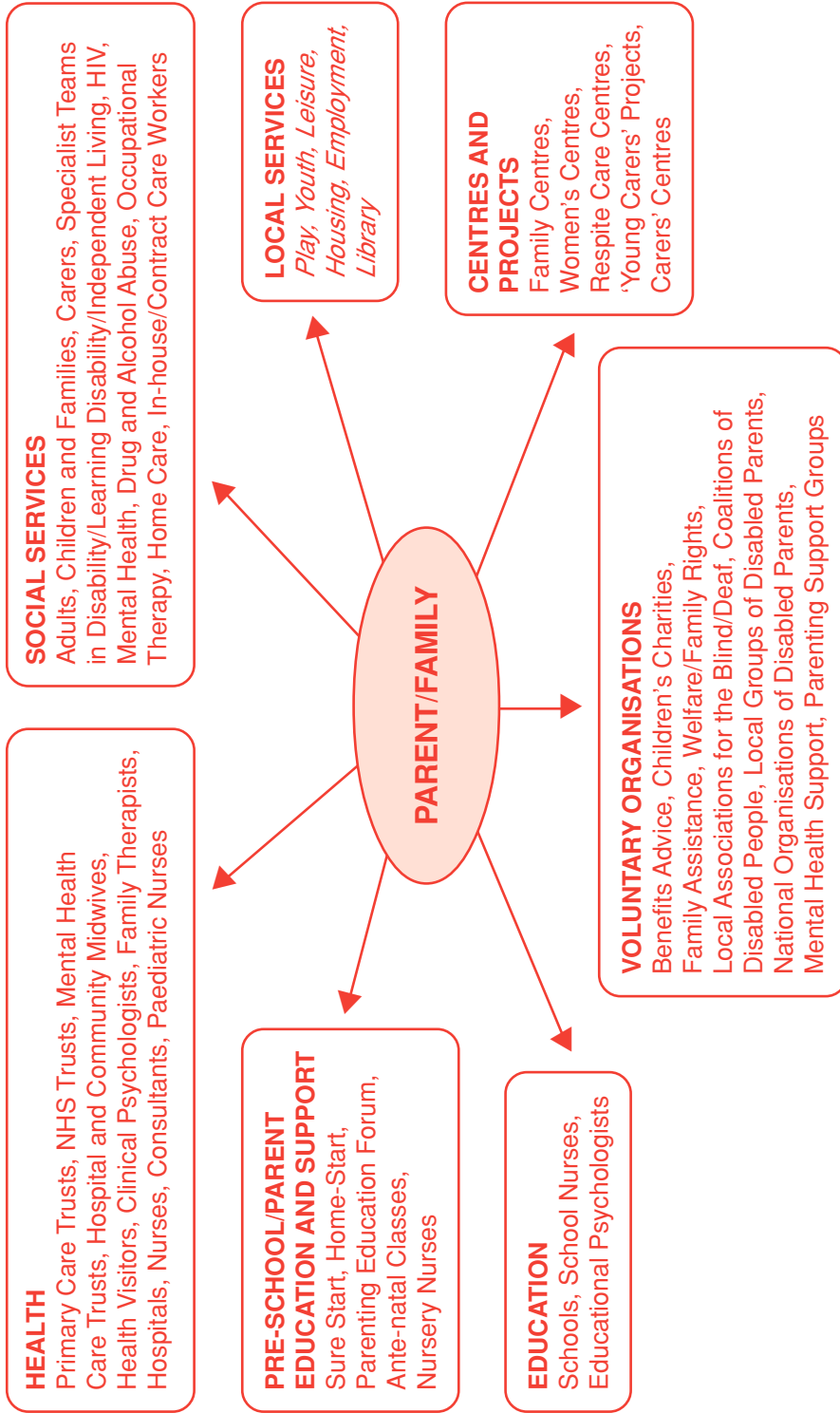
Eight of the 31 policies said they planned to initiate joint training across agencies. (No detailed information was provided, so it seemed that these plans were still at the ideas stage.) It is also impossible to know in the absence of more information whether what is planned is continuous professional learning and development or a short, one-off session.

One department hoped to provide joint training with social services (both Community Care and Children's divisions), health and education.

### Mapping exercise

In one authority, a wide-ranging mapping exercise had been carried out as part of a short-term project that included consultation with disabled parents. The extensive list of organisations and agencies consulted in the process of that project has been combined with agencies and organisations mentioned throughout the documents sent (see Figure 1). Although this list of over 50 bodies is not exhaustive, it is indicative of the range and number of potentially separate interactions that may face disabled parents in looking for support and serves as a graphic reminder of the need for joined-up working – not least because well co-ordinated services are much easier for disabled parents and their families to make sense of and find their way around.

**Figure 1 Agencies and professional organisations mentioned in the 31 policies/protocols submitted**



### Summary

This chapter has provided several examples of the creative ways in which a few social services departments – in some cases together with other agencies – are working to co-ordinate services to disabled parents and their families. Many of the plans are still in their early stages. Monitoring and evaluation of developments across divisions and agencies will be invaluable, as will opportunities to share what is being learnt. Of particular interest will be the development of interagency procedures, including arrangements for shared finance and joint training.

### Checklist

- Is service information provided to disabled parents that explains what services they are entitled to and how to go about getting hold of them?
- If so, is this information appropriate and accessible to parents from minority ethnic communities, parents with learning difficulties and Deaf parents, as well as disabled parents more generally?
- Is service allocation and provision to disabled parents subject to review?
- Do departments have procedures and staff appointed to support the development of joint working and interagency working across relevant statutory agencies and voluntary bodies?



# The way forward

## Conclusion

This research has shown that, whilst there is growing resolve nationally that the needs of disabled parents as a distinct group of service users should be addressed supportively and in a co-ordinated manner, there are unresolved issues that will need to be addressed as the direction for the development of best practice becomes established.

One of the strengths of working within the social model of disability lies in recognising that the barriers created by services (the ways in which they are provided and publicised) can be identified and removed. This enables service providers to look again at the way they are doing things and to work with disabled parents to determine how their supportive intentions can be translated into effective supportive practice. As one policy states:

*As disabled/ill people, parents encounter more barriers to participation than their non-disabled peers and as parents they are more likely to be affected by inflexibility in service provision than their disabled peers who are not parents. This policy aims to work across all agencies towards removing barriers of access, communication, stigma, and discrimination (whether arising by intention, effect or omission).*

## Key recommendations

The measures outlined below would aid local authorities in developing and implementing supportive, joined-up strategies to help disabled adults in their parenting role and in this way safeguard the welfare of children.

## Supporting disabled adults in their parenting role

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- i Ensuring that parenting tasks and roles are routinely covered within Community Care assessment and eligible for specialist adult services.
- ii Developing guidelines and good practice materials nationally to show how specialist Adult disability services can work with Children's services using both Community Care and Children's legislation constructively to support disabled parents and their families.
- ii Targeting short-term resources via Promoting Independence grants to support the development of work across social services divisions and between relevant agencies. The intention should be to establish a long-term and sustainable basis for funding services to disabled parents and their families.
- iv Using local Six Monthly Reviews and national Performance Indicators to boost development of services to this group, for example, by asking the number of disabled adults who have been assisted in parenting tasks and responsibilities.

The following are recommendations arising out of the research for good practice at local level.

- 1 The development of policy and practice should have at its heart the recognition of disabled adults' human rights to parent their children, and their entitlements to assistance in fulfilling their parenting responsibilities.
- 2 Social services departments should ensure that parenting tasks and roles are routinely included in eligibility criteria for assessment and allocation of Community Care services.

- 3 The children of disabled parents should *not* automatically be seen as children 'in need'. Rather, the aim should be to prevent children becoming in need and promote family welfare by prioritising services to support adults with their parenting responsibilities.
- 4 The use of pooled, ring-fenced budgets with contributions from Children's and Adults' services that can be accessed via adult Community Care provision provides a means of doing this.
- 5 Where child protection concerns have been identified, Children's services will be involved. In order to avoid conflicts of role and ensure that appropriate specialisms remain involved, workers linked to Adults' services should play a key role in any such cases.
- 6 The issue of providing appropriate support to parents should not be allowed, as often happens at present, to slip from service agendas where there are child protection concerns and/or where children have been removed from home.
- 7 Social services departments should recognise the importance of involving parents (including those with physical and sensory impairments, learning difficulties and mental health issues) in developing and evaluating assessments and services.
- 8 Service information should be prepared in a range of accessible formats to inform disabled parents of their service entitlements and provide clear information about how to get hold of services. This information should be made widely available. This is particularly important given that many disabled parents distrust social services, fearing that they will undermine rather than support their role as parents.

- 9 Co-ordinated practices, backed by joint training, should be developed in relation to this group of parents across divisions within social service departments and between relevant statutory agencies including maternity services, primary health care, education and housing.
- 10 Action should be taken to ensure that disabled parents have full access to services for parents generally – whether these are concerned with health, education, family support, leisure or recreation.
- 11 Ongoing monitoring of how effective policies are in practice is essential to identify both what has been found to work well and any unresolved questions/challenges.
- 12 Monitoring should also consider disabled parents' take-up of and response to the available services and the extent of their involvement in service evaluation and development.

### Some final questions

- Is the meeting of disabled adults' needs connected with their parenting responsibilities regarded as a priority for access to assessment and service allocation?
- Does the department have written policies/protocols in respect of providing services to disabled parents, i.e. parents with physical and sensory impairments, and/or learning difficulties? Do these policies include parents with alcohol, drug and mental health problems and, if not, are the service needs of these parents covered elsewhere?

- Do departments have practice and protocols that support the development of co-ordinated work in support of disabled parents and their families across relevant statutory agencies and voluntary bodies in health, education, parent education, mainstream family support, housing, etc.?
- Does the department monitor its practice, procedures and communication with disabled parents, to determine whether these are consistent with their supportive intentions?
- Does the department recognise the key role disabled parents have to play in the monitoring, evaluation and development of services and are disabled parents involved in all stages of this process?

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# Appendix 1

## Chapter-by-chapter summaries and checklists of questions for social services departments and other relevant agencies

### 1 Introduction: background to the research

#### Summary

It was encouraging to find that almost half of the social services departments that responded had done some work already, were currently doing work or reported that they had plans to do work in the near future.

The findings of this survey are in line with *A Jigsaw of Services* (DH/SSI, 2000) in that less than a quarter of departments have up to this point addressed the needs of disabled parents as a distinct group of service users in written policies and/or protocols. However, the discovery that a further quarter of departments were actively planning work in this area, and that almost half of the documents sent had been produced since the publication of *A Jigsaw of Services*, gave some cause for encouragement. It was also encouraging that in the course of the research a number of social services departments expressed interest in receiving information about good practice in other places in relation to supporting disabled adults in their parenting role. It was interesting to see that two-thirds of the named respondents/contacts were based in Adult services.

#### Checklist

- Where documents were due for review, has this happened and what was found?



- Where local authorities said that they had ‘work in progress’, has this progressed and resulted in the production of policies/ protocols?
- Are policies/protocols in use and are all relevant divisions aware of what they say?
- Where no work was planned, is this still the case?

## **2 Legislative background to disabled parents’ rights and entitlements**

### **Summary**

Both Community Care legislation and the Children Act 1989 may be used to support disabled parents, and indeed *are* being used supportively in some places. However, the absence of explicit guidance on how specialist Adult support and other services may be directed towards disabled adults with parenting responsibilities, combined with rationing and resource constraints upon both Adults’ and Children’s services, has meant that, in many places, disabled parents receive attention from service providers only after problems have arisen in respect of their children. By this stage, parent support may be low on the service agenda compared to child protection considerations. It may be that the unintended consequence of initiatives taken in relation to the Children Act may have been to ‘problematise’ disabled parents without addressing their support needs.

### **Checklist**

- Are disabled parents recognised as a distinct group of service users?

- Is service provision for them promoted and backed by a specific policy about their rights and entitlements?
- Is the entitlement of disabled adults to receive a service to support them in their parenting role both recognised in theory and upheld in practice?
- Is there a clear agreement and written policy/protocol across all service divisions specifying how Community Care legislation, in combination with Children's legislation where appropriate, is to be used to support disabled parents and families?

### 3 Eligibility and assessment

#### Summary

Analysis of the policies/protocols suggests that children can too easily be defined as 'in need' or 'at risk' or as 'young carers' without assessment being made of their parents' entitlement, under Community Care legislation, to support services, including assistance to fulfil parenting roles and responsibilities. A recurrent difficulty thrown up by the policies/protocols is that, where parenting tasks are left out of eligibility criteria for Community Care services, disabled parents will either not reach the threshold for receiving Community Care services or will not receive the additional support needed to meet *parenting* as well as personal needs. At the same time, children may not be eligible for assessment unless and until their problems are perceived as sufficiently serious. The assumption that family members will meet shortfalls in service provision may have the unintended effect of forcing partners out of paid employment or young people into inappropriate roles and/or excessive tasks.

## Checklist

- Are parenting tasks and responsibilities included in the department's eligibility criteria and covered in Assessment procedures for Adult Community Care services?
- Is the meeting of needs associated with parenting responsibilities regarded as a priority for access to assessment and service allocation?
- Do administrative workers and receptionists receive specific training in respect of responding to enquiries from disabled parents?
- Do Adult services teams record routinely that there are children in the family?
- Do Children's services teams record routinely the presence of a disabled parent?
- Are mechanisms in place that will ensure timely and effective cross-referencing between divisions in relation to disabled adults with parenting responsibilities in good time to prevent problems arising?
- Are parenting tasks and responsibilities included in the department's eligibility criteria and covered in assessment procedures for Adult Community Care services?
- Can disabled adults access the parenting support they need without their children first having to be designated as 'children in need' or 'young carers'?

- Do policies/protocols make it clear that no parent should be obliged to rely upon a family member for inappropriate levels of assistance or for help with inappropriate tasks?

### 4 Supportive intentions – supportive practice?

#### Summary

Although social services departments are aware that disabled adults are wary of approaching social services for support with parenting, they appeared to be taking few measures to allay these fears. An emphasis on children's legislation and on child protection and the comparatively small amount of attention given to Community Care legislation and providing specialist adult support mean that support for disabled adults in their parenting role may all too easily slip down the agenda where there are concerns for children's welfare. Ensuring the involvement of specialist adult workers *throughout* the contact with the family, including in cases where there are seen to be child protection concerns, gives the best chance of ensuring continuity of support to the parent and a better relationship between parents and social services.

#### Checklist

- Does the policy/protocol make it clear that the children of disabled parents are not automatically regarded as vulnerable?
- Is it possible for a disabled adult to access support for parenting without having to question whether there is a 'child in need'?

- In cases where there are child protection concerns, how is the ongoing involvement of both Children's and Adult specialist workers co-ordinated?
- Do all parents have access to advocacy services?
- Have disabled parents' perceptions of social services been evaluated?
- Are cases in which child protection measures are taken monitored to make sure that this is the most appropriate response?
- What steps have been taken to allay disabled parents' fears in relation to approaching social services departments and to ensure that services are welcoming?
- Are disabled parents involved in service development, monitoring and evaluation?

## **5 Service provision**

### **Summary**

Comparatively little attention was given in joint service protocols (though rather more in policies specific to meeting the needs of disabled parents) to the accessibility and suitability of available services. Although a lot of attention was given to the apportionment of costs between divisions, arrangements for cost *sharing* received less attention. Very few policies/protocols addressed the issue of whether charges should be waived in respect of Community Care services to support disabled adults with their parenting responsibilities.

### Checklist

- Are clear arrangements in place across divisions of social services departments and between agencies for pooling budgets and sharing costs?
- Might charging policies for parenting tasks be waived in line with a preventative approach to family support, regardless of which budget the support is funded from?
- Are Direct Payments promoted to meet parenting support needs? Since this is possible both under Community Care legislation and under the Children Act 1989, are there arrangements for joint Direct Payments packages (which might also include health services) to be made where appropriate?
- Are disabled parents consulted on their access to and experience of services intended to support them in their parenting role?
- Are specific and targeted measures in place to ensure services are accessed by and appropriate to black and minority ethnic disabled parents?

## 6 Developing supportive strategies

### Summary

This chapter has provided several examples of the creative ways in which a few social services departments – in some cases together with other agencies – are working to effectively co-ordinate services to disabled parents and their families. Many of the plans are still in their early stages. Monitoring and evaluation of

developments across divisions and agencies will be invaluable, as will opportunities to share what is being learnt. Of particular interest will be the development of interagency procedures, including arrangements for shared financing and joint training.

### **Checklist**

- Is service information provided to disabled parents that explains what services they are entitled to and how to go about getting hold of them?
- If so, is this information appropriate and accessible to parents from minority ethnic communities, parents with learning difficulties and Deaf parents, as well as to disabled parents more generally?
- Is service allocation and provision to disabled parents subject to review?
- Do departments have procedures and staff appointed to support the development of joint working and interagency working across relevant statutory agencies and voluntary bodies?

## **7 The way forward**

### **Summary**

This research has shown that, whilst there is growing resolve nationally that the needs of disabled parents as a distinct group of service users should be addressed supportively and in a co-ordinated manner, there are unresolved issues that will need to be

addressed as the direction for the development of best practice becomes established.

One of the strengths of working within the social model of disability lies in recognising that the barriers created by services (the ways in which they are provided and publicised) can be identified and removed. This enables service providers to look again at the way they are doing things and to work with disabled parents to determine how their supportive intentions can be translated into effective supportive practice.

### Some final questions

- Is the meeting of disabled adults' needs connected with their parenting responsibilities regarded as a priority for access to assessment and service allocation?
- Does the department have written policies/protocols in respect of providing services to disabled parents, i.e. parents with physical and sensory impairments, and/or learning difficulties? Do these policies include parents with alcohol, drug and mental health problems and, if not, are the service needs of these parents covered elsewhere?
- Do departments have practice and protocols that support the development of co-ordinated work in support of disabled parents and their families across relevant statutory agencies and voluntary bodies in health, education, parent education, mainstream family support, housing, etc.?
- Does the department monitor its practice, procedures and communication with disabled parents, to determine whether these are consistent with their supportive intentions?



- Does the department recognise the key role disabled parents have to play in the monitoring, evaluation and development of services and are disabled parents involved in all stages of this process?

## **Appendix 2**

### **Resources for disabled parents**

#### **National Centre for Disabled Parents**

(Home of DPN and DPPi, see below).

Unit F9  
89–93 Font Hill Road  
London N4 3JH

Freephone: 0800 018 4730

Administration: 020 7263 3088

Textphone: 0800 018 9949

Fax: 020 7263 6399

#### **Disabled Parents Network (DPN)**

Runs a peer support contact register that is open to all disabled parents, sends out a quarterly newsletter to its members and campaigns actively for improvements in services to disabled parents.

Based at the National Centre for Disabled Parents (see above).

Parent-to-parent Helpline: 0870 241 0450

Website: [www.DisabledParentsNetwork.org.uk](http://www.DisabledParentsNetwork.org.uk)

## **Disability, Pregnancy and Parenthood international (DPPI)**

Publishes a quarterly international journal and runs a UK-based information service for disabled parents and those who work with them.

Based at the National Centre for Disabled Parents (see above).

Email: [info@dppi.org.uk](mailto:info@dppi.org.uk)

Website: [www.dppi.org.uk](http://www.dppi.org.uk)

## **Policies, protocols and other useful documents**

Below is a range of documents that might be found useful. The local authorities that sent them have indicated that they are willing to share these drafts with others.

*HIV: District Wide Children and Families HIV Policy Framework*  
(2000)

Camden & Islington Children and Families Planning Group  
C/o Camden Social Services

Questionnaire: survey of disabled parents' support needs (Draft, 2001)

Royal Borough of Kingston-upon-Thames social services  
department

Disabled people: parenting needs assessment (Draft, 2000)  
Working pro forma for assessing parenting needs – seen as  
complementary to Adult full needs assessment  
Independent Living Team, Nottinghamshire social services  
department

*Oxfordshire Inter agency Policy for Parents with Disabilities, Sensory Impairment, Illness, Addiction and/or Mental Health Difficulties* (April 2001)

Policy intended as a framework for development of separate agency policies

'Consultation with disabled parents', presentation at 'Making the pieces fit', a seminar organised by Northamptonshire social services department in March 2000

Reported in DPPi (Disability, Pregnancy and Parenthood international) journal, April 2001, p.10

Parents with Learning Disability Protocol

Interagency protocol commissioned by Plymouth Area Child Protection Committee

*Supporting Disabled Parents: A Sample Protocol for Good Practice in Social Services Departments* (Tyers, H. and Wates, M.)

Available from the National Centre for Disabled Parents