

Supporting disabled adults in their parenting role

A jigsaw of services (Social Services Inspectorate, 2000) made the point that the parenting support needs of disabled adults frequently fall between adult community care provision and children's services. Michele Wates carried out a survey to find out whether social services departments have policies/protocols in relation to providing services to parents with physical and sensory impairments and/or learning difficulties and, if so, how effective these are likely to be in meeting the needs of families. Analysis of the responses from 125 social services departments and of 31 policies/protocols found that:

- f** The policies/protocols expressed supportive intentions towards disabled parents. However, in many of them it was unclear how the assessment of children's needs (using The framework for the assessment of children in need and their families) would link with community care provision to address disabled adults' parenting support needs.
- f** Parenting tasks and roles were seldom specified in eligibility criteria for assessment for community care provision.
- f** Where an adult's personal care/assistance needs apart from parenting were low and children were not seen as giving rise to concern, in many places parental support needs would not reach thresholds for receiving assessment and/or services from either adults' or children's divisions.
- f** Although policies acknowledged disabled parents' anxieties about approaching social service departments, few measures were taken to allay these fears; for example, by ensuring the continued involvement of specialist adult services where child protection concerns had been identified, or by producing accessible information specifically aimed at disabled parents.
- f** Some departments provided valuable examples of innovative work - often involving disabled parents - in developing procedures, financial co-operation and training across social service divisions and between agencies.
- f** The researcher concludes that the policies/protocols most likely to be effective are those that upheld disabled adults' entitlement to parenting assistance; reducing the risk of difficulties arising within their families by providing timely and appropriate support to disabled parents.

Background

When the Social Services Inspectorate (SSI) carried out an inspection of services to support disabled adults in their parenting role, they found that only one of the eight departments visited had a policy specific to disabled parents (**A jigsaw of services**, SSI, Department of Health, 2000). The Inspectors recommended a major shift in the approach to working with disabled parents, including a recognition of the right of disabled people to be supported in fulfilling their roles and responsibilities as parents, and the development of policies and strategies to improve 'joined-up working' across adults' and children's service divisions and between agencies.

In December 2000, the Joseph Rowntree Foundation set up a Task Force on Supporting Disabled Adults In Their Parenting Role. Members felt it would be useful to find out how many social services departments in England had policies/protocols that cover disabled parents and how far these seemed likely to address the concerns raised by the inspectors and by disabled parents. The request for information specified parents with physical and sensory impairments and/or parents with learning disabilities to avoid duplicating work carried out by the National Institute Of Social Work (**Alcohol, drug and mental health problems: Working with families** by Patricia Kearney, Enid Levin and Gwen Rosen).

The responses

Responses were received from 125 departments (82 per cent). Thirty-one departments (25 per cent) sent copies of policies and/or protocols. Most of these were drafts or in the early stages of use and review. A further 29 departments were currently undertaking work or had plans to do so. However, 63 departments said they had no plans at present to develop such documents.

Involving and informing disabled parents

Many of the policies and protocols acknowledged that disabled parents hesitate to approach social services departments for support. At worst, parents may fear that their children will be removed from home. However, few steps were taken to allay and address these anxieties. Where disabled parents had been involved in developing policies this was reflected in greater attention to disabled parents' experience of using services.

Only one department indicated that it had written information specifically for disabled parents; several others said they intended to produce something. Good practice here would be to provide information that explains service entitlements; informs and reassures parents; is in accessible formats and appropriate languages; and is widely distributed in places that parents go to, as well as places that disabled people use.

Disabled parents' entitlement to services

Many policies and protocols expressed a clear intention to support disabled parents and their families. However, there was much less clarity about the legislative routes for supporting disabled parents. This was especially evident in relation to adult community care legislation. Nearly two-thirds of the respondents and named contacts across the 125 departments were based in adults' services. Yet 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. References to adult legislation and guidance were generally diffuse and unspecific. The recommendation of the Children Act, also upheld in **A jigsaw of services**, 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 appear to have translated into consistent practice.

Restricted access to support

Only a few departments indicated that parenting roles and responsibilities should be included in eligibility criteria and assessments for community care services. This presents a barrier for adults with learning difficulties, mental health needs, physical or sensory impairments and deaf parents whose personal support needs, when parenting is not taken into account, do not reach thresholds for support.

Co-ordinating adults' and children's services

Whether the most appropriate person (adult or child or both) receives assessment, under which legislation, and at what point, depends upon timely exchange of information between divisions and agencies. The SSI inspectors found that in many places adult service teams failed to record routinely that there were children in the family whilst children's teams failed

to record routinely the presence of a disabled parent. Although many of the policies/protocols indicated the need to cross-reference information across divisions, few appeared to have established mechanisms to ensure this happens at an early stage.

A climate of rationing and resource limitation can very easily result in support issues in relation to disabled adults with parenting responsibilities not being addressed at all, becoming an issue after problems have arisen, or materialising only at crisis point. At this stage, study of the protocols suggests, the involvement of specialist adult services in relation to parent support, consultation, advocacy etc. rapidly falls away from service agendas. This can have the effect of alienating parents at a crucial point in their relationship with service providers.

Charging for services

The way that services are organised and paid for often skews provision towards existing provision rather than a service response that creatively addresses actual family needs.

Although a lot of attention was given to deciding who should pay for what, positive arrangements for cost-sharing across divisions and agencies received far less attention. In addition, very few policies/protocols addressed the issue, of crucial importance to parents, of whether community care services to support disabled adults in their parenting role should be liable to charges. A small number of local authorities specified that charges for assistance with parenting should be waived, whether under community care or children's legislation.

Parents from minority ethnic communities

Nine out of 31 policies/protocols mentioned parents from black and minority ethnic communities. Only three of these mentioned specific measures: one included questions on ethnic origin in a planned survey of disabled parents; one included advice on challenging discrimination and harassment; and a third referred to language interpretation services.

Innovative ideas and good practice examples

Several supportive measures were outlined in the policies and protocols received. These included:

- Establishing routine and co-ordinated procedures for the early identification of disabled adults with parenting responsibilities, with a view to

addressing support needs at an early stage.

- Inclusion of parenting tasks and roles in eligibility criteria and assessments for adult community care services, itemising the sort of activities this could include.
- Ring-fenced pooled budgets agreed by adults' and children's divisions to support disabled parents who would not otherwise meet standard thresholds for services.
- Promoting direct payments (including joint-funded packages across adults' and children's divisions) for disabled adults to purchase assistance with parenting.
- Waiving charges for community care services to support parenting on the basis that the aim is to prevent children from becoming children in need.
- A new development post to foster a co-ordinated inter-agency approach to supporting disabled parents (involving disabled parents, social and health services, education, mainstream parent support, housing etc.), through developing co-ordinated training, joint finance and compatible protocols.
- Practical arrangements to ensure that adult services provide specialist support, advocacy and counselling to parents in cases where children's services are involved, and that support for disabled adults in their parenting role remains on the agenda even where child protection procedures are underway.
- Stipulating that a 'young carer' assessment must automatically trigger a community care assessment of the disabled parent's support needs.
- Making it clear that no disabled parent should be obliged to rely upon a family member for inappropriate levels of assistance or for help with inappropriate tasks.
- Appointing a specialist worker dedicated to supporting disabled parents through liaison between specialist adult teams, any existing 'young carers' provision, and children and family teams.
- Involving disabled parents as advisors and partners at every stage of policy development and service review.
- Preparing accessible service information specifically for disabled parents.

Conclusion

This research has shown that whilst there is a growing commitment to meeting the needs of disabled parents as a distinct group of service users, supportively and in a co-ordinated manner, there are

unresolved issues regarding the best way to develop work across adults' and children's divisions; how to design services that offer timely and appropriate support; and how to foster co-operation between relevant agencies.

Whilst both community care legislation and the Children Act can be used to support disabled parents, the researcher concludes that the potential for holistic, timely and appropriate family support can only be realised where the role of supporting parents in safeguarding the welfare of their children is understood and steps are taken to uphold the entitlement of disabled adults to assistance with parenting tasks and responsibilities.

The researcher suggests that in addition to good practice measures at local level such as those outlined above, the following measures at national level could help local authorities in developing and implementing joined-up strategies to support disabled adults in their parenting role and in this way safeguard and uphold the welfare of children:

- Clarification of the need to ensure that parenting tasks and roles are routinely covered within community care assessments and are eligible for specialist adult services.
- Developing guidelines and good practice materials nationally in conjunction with disabled parents and their organisations 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.
- Targeting resources to support the development of work across social services divisions and between relevant agencies, with the intention of establishing a long-term and sustainable basis for funding services to disabled parents and their families.
- Using local reviews and service audits to boost development of services to this group: e.g. by asking the number of disabled adults who have been assisted in parenting tasks and responsibilities.

About the project

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. One hundred and twenty-five departments responded. In addition to examination of documents, letters and notes that came back with the responses, telephone calls with some of the respondents were incorporated into the analysis.

How to get further information

The full report, **Supporting disabled adults in their parenting role** by Michele Wates, is published for the Foundation by YPS (ISBN 1 84263 041 5, price £14.95).