









Supporting disabled adults in their parenting role

A Task Force on Supporting Disabled Adults in their Parenting Role received evidence that people with physical impairments, sensory impairments, learning difficulties, mental health difficulties, long-term illness or HIV/AIDS experience common barriers to receiving appropriate support in their parenting role. The Task Force consisted of representatives from government, social services, voluntary organisations and disabled parents' organisations. It took evidence from parents, professionals and researchers. This revealed:

-  Policies and services concerning adults and/or children are commonly developed without consulting or involving disabled parents.
-  Disabled parents find it difficult to access information and advice, advocacy and peer support.
-  There are particular problems with the relationship between children's services and adults' community care services. Work is required at both national and local level to create the framework for more appropriate service responses.
-  Disabled adults sometimes find it difficult to access their entitlements to support under community care legislation. This can lead to them having to rely on their children for assistance (i.e. their children become 'young carers').
-  Although assistance with parenting tasks should be available within the current community care framework, disabled people are often told that they can only access support through children and families services.
-  Parents often find they can only get a response from services when things reach a crisis, at which point they can be at risk of losing their children into care.
-  Mental health policy and practice does not adequately address the fact that many people with mental health support needs are parents.
-  Direct payments can provide the flexible support needed but much work remains to be done to increase the numbers of parents receiving direct payments, particularly those from minority ethnic communities, those with learning difficulties and those with mental health support needs.
-  Disabled parents experience unequal access to health (including maternity) and other mainstream services for parents and their children.
-  Disability benefits do not take account of the additional costs of parenting for disabled adults.

The Task Force on Supporting Disabled Adults in their Parenting Role met over a period of two years and heard evidence from parents, professionals and researchers about the barriers facing disabled parents, and the improvements needed to both policy and practice. Disabled parents told the Task Force that it is not impairment, learning difficulties or mental health needs which are primarily responsible for the difficulties they face. Instead, it is negative attitudes towards disabled parents and unequal access to support that too often undermine family life.

Information, advocacy and peer support

The Task Force received evidence that parents find it very difficult to get the information they need. Other disabled parents are key sources of information and advice. Health and social services professionals often do not have relevant knowledge or expertise, and neither do voluntary sector parent support organisations. Information and support aimed at parents are often not accessible to disabled parents and do not deal with their particular concerns – including fears about seeking help from statutory services.

Disabling attitudes

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

Both social care and legal professionals often hold the views that disabled parents are considered to be in need of ‘care’ rather than in need of assistance; and that their children would be better off with a non-disabled parent. These disabling attitudes can result in action that at best results in inadequate and inappropriate services and at worst means parents lose their children into care.

Community care policy and practice

Disabled people are entitled to receive an assessment of their needs for community care services and, if they meet the local authority’s eligibility criteria, to have those assessed needs met. They are also entitled to be offered direct payments in lieu of services. Yet the Task Force heard evidence of situations where children are identified as ‘young carers’ and the only help the

family is offered concerns enabling the child to carry on being a ‘young carer’. Although a few local authorities are working hard to develop good practice in supporting disabled parents, evidence was also heard of children being removed from their parents, without an assessment of any sort being offered to parents in terms of their own support needs.

Disabled parents stressed that assistance with parenting tasks should be available from adult community care services, a view also held by the Association of Directors of Social Services. However, current government guidance does not make this clear and the Task Force received evidence of situations where parents were told to contact the Children and Families section of their social services department for such assistance. Parents did not want their children to be labelled as ‘in need’ and argued that their own entitlements to support under community care legislation should be recognised.

Particular concerns were expressed about parents who were labelled as having ‘mild to moderate learning difficulties’ and did not fit the eligibility criteria of support services for adults with learning difficulties. Parents can find that social services will only respond when their children are identified as ‘at risk’ and they are then vulnerable to losing their children into care.

Direct payments are an important way for disabled parents to have choice and control over the assistance they need. However, take-up of direct payments remains low and inconsistent across the country. It is particularly uncommon for people from minority ethnic communities, with learning difficulties or with mental health support needs to receive direct payments. It is also very unhelpful that the Trust Deed of the Independent Living Fund says that ILF grants can only be used to meet assessed needs for personal care and domestic assistance, and not for childcare or support needs related to parenting a child.

Children and families services

Disabled parents told the Task Force that they felt many assessments are dominated by a focus on parental ‘incapacity’ instead of a focus on support which would enhance parents’ ability to look after their children. Family assessment centres should be accessible to, and knowledgeable about the needs of, disabled parents. Early support, delivered in a non-judgmental and empowering way, can make all the difference to parents’ ability to look after their children. However, this is not always available.

The Task Force heard that it was uncommon for children’s services to work together with adult community care teams. This has meant that some

disabled parents, particularly those with learning difficulties and those who are users of mental health services, have had children taken into the care of the local authority without their entitlement to support under community care legislation ever having been assessed or addressed.

Current developments in children's and adults' services

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

Poverty and the benefits system

There is little research on the socio-economic circumstances of disabled parents but research on 'young carers' has generally found poverty to be a common experience amongst these families. The benefit system recognises the additional costs of parenting a disabled child, but the additional costs of parenting because of parental impairment or ill health are not acknowledged. Disabled parents told the Task Force that they incurred additional expenditure over and above the usual costs of parenting. Examples included increased reliance on convenience foods; increased use of more expensive social activities (because cheaper options are inaccessible); paying for assistance to support parenting tasks; paying a support worker's costs when going out; costs of specialist or adapted equipment; increased transport costs; increased reliance on childcare.

Health services

Lack of accessible and up to date information about health services was a key issue identified by disabled parents. They also spoke of inaccessible environments and equipment in ante-natal, maternity and post-natal services. Again, parents identified that the attitudes of professionals could have a huge impact on experiences of service. An example was given of a midwife who was willing to search out ways to make her service suitable for a disabled woman. One hospital had a designated member of staff whose job it was to check that disabled parents' needs are planned for and met appropriately. However, these

good practice examples seemed to be uncommon and there was also evidence of significant barriers to accessing health services, including maternity services.

Education

Disabled parents told the Task Force that it could sometimes be very difficult to fulfil their role as parent in the context of their children's education. They told of situations where schools were physically inaccessible to them, where information was not available in appropriate formats and where they experienced negative attitudes towards them and their children. At a policy level, the needs of disabled parents in the context of their relationship with schools and education authorities have only been recognised via the identification of children as 'young carers'. Some parents have reported that identifying their children as 'young carers' can mean that teachers have low expectations of their children's potential. Task Force members felt that schools should be encouraged to develop good practice in their relationships with disabled parents and to fulfil their obligations under the Disability Discrimination Act.

The need for research

The lack of a strong, credible body of evidence about 'what works' in supporting disabled parents weakens the potential to influence policy development and increase the understanding of policy makers and practitioners. So far most research has focused on 'young carers' and this may have resulted in some skewed policies and practices in supporting these children and their parents. The Task Force was told that research should involve disabled parents and their families, and be able to answer the question of 'how this will make a difference'. The Disabled Parents' Network has called for quantitative research designed to provide specific information that could assist policy-makers and practitioners and the Task Force backed this recommendation.

Conclusion

Based on this evidence, the Task Force made a number of recommendations for improving the practice of the following bodies:

Department of Health

- in consultation with organisations of disabled parents, develop a national protocol and practice guidance for the assessment of the needs of disabled parents;
- issue clear guidance that adult community care assessments should include assistance with parenting tasks;

- develop a Performance Indicator on the take-up of direct payments amongst disabled parents;
- take account of the needs of parents with mental health difficulties when developing mental health policies;
- fund research into examples of good practice in maternity services, develop protocols for maternity services to address the needs of disabled parents, and disseminate these to all maternity services;
- encourage all health services which address the needs of parents to carry out disability audits of their premises, procedures and practices to ensure that they comply with the requirements of the Disability Discrimination Act 1995.

The Valuing People Support Team:

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

The Independent Living Fund:

- amend the ILF Trust Deed so that support with 'family roles and responsibilities' can be included in the needs which can be met by an ILF grant. This would be in line with Department of Health guidance, *Fair access to care services*.

Department for Education and Skills (relating to children's services):

- amend *Working together to safeguard children*, to require social workers to ensure that disabled parents receive assessments of, and responses to, their need for support under community care legislation before decisions are made about the capacity of parents to look after their children;
- revise the *Framework for the assessment of children and their families* to take account of the support needs and entitlements of disabled parents.

Social services departments:

- in consultation with organisations of disabled parents, develop protocols for the assessment of the needs of disabled parents;
- promote direct payments for disabled parents;
- examine the operation of their charging policies in terms of how they affect disabled parents, and make any changes required to ensure that they do not create perverse incentives for disabled parents to identify their children as being 'in need' or as 'young carers';

- develop joint working across children's and adults' services to ensure appropriate referrals and that children do not become 'young carers' or are taken into care as a result of a lack of support to disabled adults.

Other recommendations were made to the new Commission for Social Care Inspection, the Department for Work and Pensions, the Association of Directors of Social Services, parent support organisations and to organisations involved in the training of health and social care workers, and lawyers. These are covered in more detail in the main report.

About the project

A Task Force on Supporting Disabled Adults in their Parenting Role was set up by the Joseph Rowntree Foundation, with support from the Department of Health, the Association of Directors of Social Services, the Disabled Parents' Network and relevant voluntary organisations. Members also included disabled parents. The Task Force met seven times over two years and also hosted two conferences to which non-members were invited. Parents, professionals (including government civil servants, social work practitioners and representatives from the voluntary sector) and researchers were invited to make presentations and contribute to discussions around themes identified at the first meeting of the Task Force in December 2000. The full report summarises the evidence heard by the Task Force and sets out detailed recommendations for the different agencies concerned.

How to get further information

The full report, **The right support: Report of the Task Force on Supporting Disabled Adults in their Parenting Role** by Jenny Morris, is published by the Joseph Rowntree Foundation (ISBN 1 85935 134 4, price £14.95).

