

# Disabled Parents And Their Children: Building A Better Future

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## SUMMARY

Parental disability

When we consider disability and its impact on children, we often confine our thinking to disabled children and to the support they and their families need. However, there is a much larger group of children, who may or may not be disabled themselves, who live in households containing a disabled parent. Attention has rightly been given to the ways in which disabled children are socially excluded both through inadequate resources and social attitudes. However, rather less attention has been paid to children who experience social exclusion as a result of their disabled parent's restricted access to employment, housing, transport, hospitals, primary health care and their children's schools. In challenging the social exclusion of children, we need also need to consider the impact of disadvantage and discrimination on disabled adults with parenting responsibilities.

Parental disability remains a curiously hidden phenomenon. Infirmity is not commonly associated with parenthood, at least not before old age. Yet large numbers of parents - some 15% of parents in the UK according to the Labour Force Survey - will experience temporary or permanent

disability while their children are still minors. Drawing attention to the support needed by disabled parents without further compounding the difficulties they may face is a challenging task. Raising public awareness of the situation of disadvantaged groups – whether children or adults – has traditionally meant emphasising their vulnerability, neediness and weakness. However, confident and competent parenting is good for both children and their parents. Parents, whether they are disabled or not, need to feel in control, and children need to perceive them as being in control.

## Social Exclusion

There is growing evidence that the support requirements of disabled parents are insufficiently met by mainstream education, and health and family services. While trying to access more specialised services, disabled parents can fall through the gap between child and adult provision. As a result it may be difficult, and sometimes impossible, for disabled parents to access the information, equipment, resources and assistance they need in order to prevent problems arising. Disabled parents frequently report that the process of seeking this support unjustifiably stigmatises them and their families. There has been concern for some time about the number of cases in which disabled parents, particularly parents with learning disabilities, have lost custody of their children – either through child protection proceedings or in disputes over residency following the break-up of parental relationships – without their support needs in relation to parenting having been assessed or addressed. In many local authorities there may be no planned response to disabled parents with parenting responsibilities unless and until problems arise for children. This is counter to both the intentions of the Fair Access to Care Services (FACS), which states that any needs that a

disabled person may have in relation to parenting should be thought about as part of community care assessment, whilst guidance to the Children Act 1989 says that where disabled parents have support needs these should be addressed in order to uphold children's welfare wherever possible in the context of their own families.

The needs of disabled parents, their partners and children should be met alongside those of other parents and families. Where parents have additional specialist needs these should be addressed in good time to prevent more serious problems from arising.

**Disabled Parents and Young Carers** Given the substantial numbers of both parents and children affected, parental disability and its policy implications have remained a relatively marginal issue in the social welfare universe. Since the late 1980s, a substantial literature has emerged which has highlighted the situation of children and young people who deliver physical or emotional care to family members. Young carers and their circumstances have been extensively reported and dedicated services under the provisions of the 1989 Children Act and its Scottish and Northern Ireland analogues, and their right to an assessment and services, upheld through the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000. Somewhat more recently, and in response to growing lobbying by disabled parents, a series of reports and studies have been published which have focused more extensively on the unmet support needs of disabled parents. Tensions, which reflect changing attitudes towards both childhood and disability in the wider social environment, have emerged between the different constituencies involved in this debate. How can we achieve a more constructive perspective on the relationship between the needs of parents, the needs of

children and the needs of families? How can we continue to support children in very difficult circumstances while not undermining the status of parents? How can we reduce the frequency with which children have to care for disabled relatives? Can we promote the welfare of children without recourse to images of impairment and disability that are patronising and demeaning to disabled people?

Content of the Report This discussion document addresses these questions and a wide range of associated issues in the following chapters.

An Introduction by *Michele Wates* and *Tony Newman* outlines the main issues and provides details of numbers of disabled parents, their dependent children, and their circumstances. *Richard Olsen* provides an historical overview of disabled parents and the current policy context. *Michael Preston-Shoot* explores the legal context as it applies to disabled parents and their children. *Tony Newman* reviews the research literature on parental disability and its impacts on children. Finally, a dialogue between *Jo Aldridge* and *Michele Wates* analyses some of the commonalities and differences between those involved in developing services for disabled parents and young carers.

Who and what is this report for? Barnardo's is one of many organisations concerned with the effective delivery of services to disabled parents and their children. The continual improvement of services requires both reflection and action. The material in this report is designed to stimulate our own creative response to the situation of disabled parents and their children, as well as the responses of others. It will be of interest to all those involved in supporting disabled parents and their children, which is a wide constituency embracing those who work in both child and adult services.

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