

Children in Care, Children who Care: Parental Illness and Disability and the Child Care System

A report prepared for the
Calouste Gulbenkian Foundation

by Chris Dearden and Saul Becker
Young Carers Research Group
Loughborough University
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The Young Carers Research Group

The Young Carers Research Group (YCRG) based at Loughborough University was established in 1992 under the directorship of Dr Saul Becker. The Group conducts applied research and policy evaluation concerned with community care, children and young carers' issues, and works in close collaboration with a multi-agency steering committee and national organisations concerned with carers' issues, particularly the Carers National Association, Crossroads, and the Calouste Gulbenkian Foundation. The Group currently has three contract funded researchers, Jo Aldridge, Chris Dearden and Betty Newton.

The Group's project work has included: a study of young carers in Nottinghamshire; a follow-up study of young carers' parents; a study of young carers' experiences in France, Sweden and Germany; a briefing pack for UK professionals; the first directory of young carers' projects in the UK; an audio training pack for UK professionals on young carers' issues; a resource and information pack for young carers; the production of principles and guidelines for young carers' befriending projects and an evaluation of a young carers project. The Group's latest report, *Young Carers - The Facts*, is the largest study ever conducted on young carers and was published by *Community Care* magazine in November 1995.

In addition to this work members of the Group have presented papers and seminars at over 30 international, national and local conferences and have published numerous reports and articles for journals. Over the past three years the Group has been at the forefront of developing awareness of young carers' needs and rights amongst professionals and policy makers in the UK and abroad. Since its formation in 1992 the Group has received 14 externally funded contracts from local authorities, health authorities, voluntary and charitable organisations and trusts. It has also worked closely with the Department of Health Social Services Inspectorate in raising awareness of young carers' issues. A number of documentaries have been made focusing on the work of the Group, including a 'World in Action' report broadcast in October 1995. Findings of the Group have also featured in every quality newspaper.

In 1997 the Group commenced two new projects, in partnership with the Carers National Association and with the financial support of the Calouste Gulbenkian Foundation: a new edition of the *National Directory of Young Carers Projects* and national monitoring of the Carers (Recognition and Services) Act.

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Introduction

Research into the needs and experiences of young carers - children and young people providing 'informal' care for ill or disabled family members - has uncovered evidence of some young carers having been looked after by local authorities, and others for whom the possibility of care proceedings is perceived as a threat which causes fear and anxiety (Elliott, 1992; Aldridge and Becker, 1993, 1994; Landells and Pritlove, 1994; Dearden and Becker, 1995; Frank, 1995). While none of the research has concentrated specifically on this issue, it is a theme which has been raised in various conferences and seminars designed to enhance the profile of young carers and to raise professionals' awareness of the issue. Our interest in the area stems from our earlier research into the experiences of young carers, our contacts with them, their families, and with professionals from health, social services, education and the voluntary sector. Many of these professionals are aware of the links between young caring and the child care system.

In this report we review the incidence of children being 'looked after' as a result of parental illness or disability; we explore whether fears of professional intervention are justified, and indeed whether professional intervention need be feared at all; and we examine how social work and other professions could be used to support the children of ill or disabled parents, to prevent care proceedings or to minimise fears of such proceedings.

The Incidence of Children Looked After Because of Parental Ill Health

The Children Act 1989 uses the term 'looked after' to denote children who are accommodated (voluntarily) or the subject of care and supervision orders. Much of the literature pre-Children Act refers to children being 'in care' and, indeed, many children and families continue to use this term. We have tried, wherever possible, to use the term 'looked after' and we refer to the 'child care system' when we are speaking about residential or foster care, whether this is the result of (voluntary) accommodation or a court order.

Official statistics show that 48,800 children were looked after at March 1995, a decrease from 49,900 the previous year (Department of Health, 1996a). Of these, 2,300, or five per cent, were classified as being looked after because of their parents' health. During the same year, 31,100

children *started* to be looked after, 4,200 because of ‘parents’ health’. This is the third most common reason for those entering the child care system, following ‘parents need relief’ and ‘abuse or neglect’ and accounts for 14 per cent of the total number of children entering the child care system in that year. Of those who *ceased* to be looked after in the same period, 3,900, or 12 per cent had been looked after because of parental ill health. These figures are broadly similar to the previous year when parental ill health accounted for four per cent of the total number looked after, and for 15 per cent of those starting and 13 per cent of those ceasing to be looked after (Department of Health, 1996b).

The statistical significance of parental ill health influencing the likelihood of children entering the child care system is thus quite high, accounting for about one in seven of those entering the child care system and being the third most common reason for admission. Furthermore, because more children enter the care system as a result of parental ill health than leave it, it appears that care is not a short-term experience for some children whose parents are ill or disabled. These figures cannot tell us the length of time such children remain within the system and what their experiences are once in the system. A further caveat is that these official figures will exclude other children for whom parental illness was a *factor* in their admission to the child care system, but not the ‘official’ reason recorded. For example, Dearden and Becker (1995) interviewed siblings, Cathy and Sean, who were removed to a place of safety as a direct result of their mother’s poor mental health. Because these children were considered to be at risk, parental ill health would not have been the reason *recorded* for their entry into the system and yet it *was* the overriding factor. Anecdotal evidence from colleagues in academic and practitioner roles suggests that poor parental *mental* health is a common factor, but is not always recorded as the official reason for entry into the child care system. The most common reason for children being admitted is ‘parents need relief’ and it is highly likely that some parents may need relief partially because of poor health or disability; this category may therefore disguise some children for whom parental ill health is a factor in their admission to the system.

Other research (Aldridge and Becker, 1993) highlights how some young carers have experienced the threat of care proceedings as a result of repeated absence from school. Since the Children Act 1989, this is no longer sufficient grounds *on its own* for care proceedings, but again demonstrates how children of ill or disabled parents might have previously entered the system without their particular experiences being acknowledged: they were missing school as a result of their caring

roles *and* in the absence of outside support. Missing school is a common problem with many young carers (Dearden and Becker, 1995; Mahon and Higgins, 1995; Marsden, 1995) and is likely to bring them to the attention of professionals.

There are no research studies which concentrate specifically on children looked after because of parental ill health. Indeed, the research on children *in* care seems to have largely ignored the issue of parental illness or disability and its association with children *who* care. However, much of the research does refer to parental illness, either overtly or obliquely. For example, Bebbington and Miles (1989) studied the background of 2,500 children entering care in 1987 and drew comparisons between their own findings and those of Packman (1968) 20 years earlier. They suggest that, in addition to major Acts and increased public attention, there has also been a shift in emphasis resulting in deprivation being viewed less as a social malaise and more as an individual or behavioural problem. This emphasis on the behaviour of families has highlighted parental problems, *including parental mental health*, as factors in child care proceedings. They identified several factors which increase the likelihood of children entering the child care system, including broken families, poor housing, receipt of benefit, very young mothers or large families, and suggest that deprivation was a common factor in all children entering care. These factors have been found to be significant in other studies (see for example Becker and MacPherson, 1986; Becker, 1997).

Although there is no discussion of parental illness or disability in Bebbington and Miles' indicators of need, several of these indicators can be linked with poor health or young caring situations. For example, in a national study of young carers supported by projects (Dearden and Becker, 1995), 60 per cent of the children were from lone parent families. The links between poor health and poverty have been long established (see for example Black, 1980; Whitehead, 1987) and many young carers are living in lone parent families headed by an ill or disabled parent, particularly a mother, who is highly likely to be dependent on benefits, especially means-tested social assistance (income support). Bebbington and Miles also suggest that the high number of children from lone parent families entering the care system is not simply the result of poverty and deprivation, but may also reflect a breakdown in other social networks. Again, when we look at the situation of young carers, we find that they often experience limited social networks and support (Aldridge and Becker, 1993).

The research evidence suggests the existence of a complex interplay of factors, including ill health,

family structure, financial means and external support, which, when combined, increase the vulnerability of some families to having their children received - voluntarily or reluctantly - into the child care system.

A comparison between Bebbington and Miles' (1989) findings and those of Packman (1968) shows that the incidence of parental ill health as a reason for (voluntary) admission fell from 56 per cent in 1962 to 19 per cent in 1987. No explanation is offered for this, but the incidence of children admitted to the system under a court order increased more than threefold, so this may simply reflect an increased use of compulsion in preference to the voluntary route. Equally, parental ill health may be disguised within another category. Nevertheless, on the face of it, the incidence of children in the care system as a *direct* result of parental illness may have decreased since the 1960s.

Decisions Regarding Child Care

Decisions regarding child care are not taken in a vacuum but reflect political, societal and professional concerns and changes. Frost and Stein (1989) suggest that inequality is the key organising concept in any analysis of child welfare in modern Britain, and that there are connections between family forms and historical and political constructions of childhood and child welfare. Thus, they argue, 'childhood' is socially constructed and British social policy rests on the premise of the nuclear family - two parents and children sharing a discrete home - which is not reflected in the reality of many households today. This emphasis on the nuclear family, and the implicit notion that the family provides a nurturing environment, ignores the fact that many children have negative experiences of family life, and leads to problems within families becoming individualised and 'pathologised' - 'problem families', rather than families with problems.

Frost and Stein trace the history of child welfare from feudalism to the post-war years, showing how notions of childhood are incorporated into the child care and welfare system, and how both are affected by ideology and perspectives on social problems and the role of the state. Thus, in a feudal society orphans and illegitimate children were cared for by the community; in the sixteenth and seventeenth centuries children were simply part of the masses, to be apprenticed or placed in some form of work; following industrialisation illegitimacy became further stigmatised and many children were abandoned, sold or even drowned; the nineteenth century saw the beginnings of child welfare and some of the now famous child rescue organisations such as Barnardo's.

During the twentieth century there have been several shifts in ideology and emphasis. The early years saw the first acknowledgement of the protection of children's rights although reform was 'statist as opposed to philanthropic, but minimalist as distinct from socialist' (Frost and Stein, 1989: 31). In the early post-war years came the Children Act 1948 and a move away from biological determinism and 'victim blaming' towards a psychoanalytical approach. The work of Bowlby was influential in emphasising the importance of a maternal figure, and preventive work with families, as a means of supporting them rather than institutionalising their children, became popular in the 1950s. During the 1970s, social work became professionalised, the post-war consensus began to crumble as the escalating costs of the welfare state were acknowledged and poverty was 'rediscovered'. Welfare rights, advocacy and community work were adopted as strategies towards redressing social deprivations, and foster placements were preferred as temporary rehabilitative measures, rather than permanent alternatives. The rise of new right ideology in the late 1970s led to authoritarian populism and individualism with a renewed emphasis on 'victim blaming' and biological determinism. Whilst children's rights have become of greater concern, so parental responsibilities have been emphasised and the poor and deprived have been blamed for their own poverty and deprivation. As Millham *et al.* (1986: 37) state:

The historical antecedents of much child-care legislation has a punitive aura and is administered in an adversarial way.

Throughout history therefore, the way the 'problem' of child welfare has been viewed has affected the actions taken and policies advocated. Central throughout has been the deprivation associated with orphans and illegitimate children; with beggars and the destitute (including children); with the children of the dangerous, feckless classes; and with those of 'problem' families (Frost and Stein, 1989). In more recent years clear links have been made between social deprivation, poverty and admission to the child care system (Becker and MacPherson, 1986, 1988; Becker, 1997). This has been exacerbated by the increasing isolation of many families, the breakdown of the nuclear family and the increase in unemployment and poverty:

One indication of the impact of economic restructuring upon social relationships was the circumstances in which children were admitted to care between the 1950s and the mid 1970s. The 'short-term illness of parent', 'desertion by partner other parent unable to care', 'long-term illness of parent', became the major categories for reception into care and clearly reflected the increasing social isolation of families from their extended networks and community support (Frost and Stein, 1989: 99).

In a study of decisions regarding admission to care, Packman, Randall and Jacques, (1986) looked at all decisions made regarding care in two port towns over a twelve month period. Parental health problems were present in many cases, although more common in those admitted to care than those whom social workers decided not to admit -21 per cent compared with 10 per cent. Of those admitted voluntarily, more maternal illness was recorded, with 38 per cent of mothers reported as recently ill. The children admitted to care were grouped under three headings: ‘villains’, who were admitted because of their own behaviour; ‘victims’ whose own behaviour was not considered to be a factor; and ‘volunteered’ who were admitted to voluntary care for a variety of reasons. Parental health problems figured in all groups:

Figure 1: Parental health as a factor in admission to the child care system

	Villains	Victims	Volunteered
Mother recently ill	29%	30%	38%
Parental health as an element of problem	2%	3%	45%
Parental health as one of main reasons for admission	4%	21%	49%

Source: Adapted from Packman et al. (1986)

Although parental health problems are not as noticeable where children were admitted to care because of their own behaviour, (the exception being the recent illness of a parent), they are a major factor for both of the other groups - the victims and the volunteered. Indeed, almost half of those in voluntary care were there as a result of parental illness.

Packman *et al.* (1986) sought the views of both social workers and parents regarding the decisions made. Social workers considered that 30 per cent of the mothers, but only six per cent of fathers, had some form of mental disorder; that seven per cent of mothers, and nine per cent of fathers, had a physical disability; and that one in ten mothers, and slightly fewer fathers, were in poor health. They considered parental poor health to be a *key element* in the decisions made for 15 per cent of children. Parents placed more emphasis on poor health, with 35 per cent of mothers and 20 per cent of fathers reporting poor health at the time decisions regarding child care were being taken. Opinions regarding poor health were subjective in all cases, with no attempts made to measure this objectively. Nevertheless, ill health was a significant factor in many cases, and when the cases were reviewed after six months social workers considered ill health to remain a factor in one in five cases.

In addition to parental ill health, Packman and colleagues (1986) also found evidence of the indicators of need later identified by Bebbington and Miles (1989). For example 40 per cent of the children came from lone parent families and only 43 per cent from families consisting of two, married adults. There was evidence of many new relationships such as step parents and siblings, half siblings etc. Forty four per cent of the children came from families where there was no wage earner and over half lived in council accommodation. Some of the families were isolated from the wider extended networks, and others were marginalised with little support even if they were living in close proximity. Although interviews with both social workers and parents accorded in relation to family composition, families did not perceive relationships, either marital or with wider kin, to be as 'bad' as social workers' perceptions. They were however, more likely to be dissatisfied with housing and neighbourhood.

The findings of the study suggest a certain amount of discord between social workers' and parents' perceptions of situations prior to child care decisions. Furthermore, in spite of the fact that many of the parents had wanted their children to be cared for elsewhere, some still expressed dissatisfaction with social workers and with outcomes. These findings indicate that social work decisions are to some large extent based on subjectivity and reflect professional interpretations of events and situations. A government review of research into decision-making suggests that decisions are often rapid and unplanned, frequently occurring at crisis point, and differing perspectives of parents and social workers may go unrecognised (DHSS, 1985).

It has already been established that poverty and deprivation are major factors in determining the outcome of child care decisions, and Fisher *et al.* (1986) suggest that this fits with notions of a cycle of deprivation, supported by Keith Joseph, a leading right wing thinker in the first Thatcher government, the first secretary of state for Social Services in the early 1970s and the initiator of the decade-long Social Science Research Council programme of research into deprivation. This theory suggests familial characteristics which single out the poor as being different and likely to reproduce their poverty inter-generationally. This deterministic approach can be used in a punitive way, to remove children from 'bad' environments and replace poor parenting with institutional care and control. Although the studies by Fisher and colleagues (1986) and Packman and colleagues (1986) are somewhat dated, biological determinism remains on the social policy agenda with theorists such as Murray (1990, 1994) arguing that many lone, never married mothers form part of an underclass which is set apart from the rest of society because of its deviant values and norms. Thus the children

of poor families are much more likely to be viewed as 'undeserving' and to have their children received into the child care system. Ill or disabled parents, particularly lone parents, face multiple problems of poverty, ill health, reliance on benefits etc. and are therefore even more vulnerable to negative labelling and loss of their children.

The research by Fisher and colleagues (1986) found that it was not always possible to identify the specific reasons for admission to care and that many families had experienced 'problems' over a long period of time. A third of the cases in their detailed study of 55 children from 31 families were lone parent families headed by mothers who often expressed problems concerning discipline. Many mothers had a fatalistic attitude to events - a sentiment not anticipated by the researchers who had rather expected anger or resentment of professional intervention. Child rearing was viewed by many to be demoralising and left them feeling powerless - admission to care was simply another example of this powerlessness. However, they also found evidence of parental frustration that their particular experiences were not acknowledged and that they were judged to be bad, incompetent or ignorant. The discrepancies between parental and professional expectations and interpretations of events found by Packman *et al.* (1986) were also evident in Fisher and colleagues' (1986) findings, with parents perceiving problems in terms of their children, but social workers judging them in terms of family relationships. Given that these discrepancies and conflicts were apparent at the outset, it is not surprising that care was viewed in a different light by both groups. Families viewed care as a means of improving the *child's* behaviour, whilst social workers viewed it as a last resort due to a failure to sort *out family* problems.

The research reviewed suggests that entry into the child care system is often unplanned and occurs at crisis point. For children who are young carers and for their parents, this is the type of intervention most feared and this fear often prevents them from seeking the support which may, ironically, help to prevent their admission to the child care system. We would suggest that in families where children are acting as carers, there is a high likelihood of their admission because they often experience the multiple deprivations associated with being looked after. Furthermore, these deprivations may ultimately result in caring relationships breaking down so that they become 'failed' young carers - children who have cared for a parent but who are admitted to the child care system because of a combination of factors such as poverty, deprivation, illness, absence from school etc., in addition to and partially because of the lack of social care support afforded their parents.

We are not suggesting that *all* children admitted to the system as a result of parental illness are young carers. Some may be looked after for brief periods when a parent is in hospital, for example, and may never again enter the system. However, the high numbers of children looked after as a result of parental illness or disability; the fact that some experience care as a longer-term arrangement; and the fact that many young carers and their families fear their admission to the child care system and refrain from requesting support because of these fears, coupled with the fact that they may be suffering multiple deprivations, all suggest that many of the children within the system may be or may have been young carers.

We will now look at children's experiences once they have been admitted to the child care system.

Parent-Child Contact

Concern was expressed during the 1970s regarding parent-child contact for children in residential or foster care, and a longitudinal study in the mid 1980s (Millham *et al*, 1986) sought to look at children's 'careers' in care; the care experience and separation; and negotiations between individuals and the state. They looked not only at direct links between parents and children, but also at indirect links such as letters, telephone calls, contact with the wider family etc. They were also interested in 'feelings' of links such as having the power to intervene in situations. As with other studies, parental illness was a factor in the care careers of some children. Nine per cent of their sample of 450 children were referred to social services departments because of parental illness, although the authors acknowledge that the reason for referral may not always be the ultimate reason for admission, and it is evident from their research findings that considerably more than nine per cent of the children came from families where a parent suffered ill health. Other indicators of deprivation or need were also apparent - a third of the children were illegitimate and 45 per cent living in lone parent families at the time of admission:

Thus, the family unit is unstable so that when illness strikes or the electricity is cut off, there is little resource on which to fall back (Miltham *et al*, 1986: 51).

This lack of resources may be one reason why decisions are often taken quickly, at crisis point, with little forward planning. This lack of planning can, according to Millham and colleagues, contribute to barriers to contact between parent and child. Such barriers include both specific and non-specific limitations on contact. Specific limitations are usually imposed by courts but non-specific limitations can be the result of several factors, for example distance from placement, other

commitments, health problems etc. Millham *et al* suggest that maintaining contact through *any* separation can be difficult, but that links with children in care can be even more problematic. This may be a result of the emphasis placed on parenting and the importance placed on the nuclear family which result in separation being viewed a failure:

We have already seen that poverty, exacerbated by isolation and ill health, puts intolerable pressure on some families and that the juxtaposition of many pressures precipitates their children into care ... indeed, some mothers fail to seek medical care for both physical and mental problems, haunted by the prospect of losing their children and the unequal fight to get them back (Millham *et al*, 1986: 117).

Fears of losing children may be justified in terms of the loss of parent-child contact, evident in Millham and colleagues' work. Where children had left care within six months of entering it, they found that non-specific restrictions to contact were evident in 70 per cent of cases and that health problems affected links in 29 per cent. However, a third of all children leaving care early did so because of an improvement in their mothers' health or discharge from hospital, and:

Health and economic problems also abound with no fewer than 43 per cent of the children coming from families where a member suffers a serious or chronic illness (1986: 126).

Thus many children of ill parents do leave care early, sometimes due to an improvement in parental health, but families often face barriers to contact which can, in some circumstances, make return home more difficult. The failure of some parents to seek medical help because of their fears concerning separation of the family reflects the reluctance of some parents of young carers to seek social care support lest they be found wanting as parents (Aldridge and Becker, 1994). However, not seeking support is likely to exacerbate the social problems of these families, is more likely to result in their children becoming the main carers and, ultimately, is more likely to result in their admission to the child care system.

Many of the problems concerned with parent-child contact were taken into account in the Children Act 1989. Bullock *et al*. (1991) indicate that the barriers to access, suggested in studies such as that by Millham and colleagues (1986), constitute *de facto* terminations of contact, rather than *de jure* terminations decided by courts. The Children Act 1989 outlines parental responsibility - the rights powers, duties and responsibilities which parents have - which is only lost on adoption, although it can be limited in some ways following care and protection orders. Since the Act assumes parental

contact under Section 34 and emphasises parental responsibility, any future restrictions will be *de jure* and *de facto* ones will be illegal (Bullock *et al.*, 1991). However, a more recent study (Bilson and Barker, 1995) has found that of 848 children in three local authorities, two-fifths had *no* face-to-face contact with their parents and less than half saw them once a month. The children in this study were looked after for a variety of reasons including what Bilson and Barker termed 'misfortune' which includes those whose parents were unable to look after them because of physical or mental illness. These children were more likely to be placed in foster rather than residential care. However, Bilson and Barker's findings suggest that children looked after in foster placements are less likely to have contact with their parents than those in residential care. Some of the children in this study had been looked after for some considerable time, therefore the emphasis on contact contained within the Children Act may not have been evident when they were first in the care system. Nevertheless, this study confirms the findings of Millham *et al.* (1986) suggesting that we have some way to go before the Children Act remedies many of the problems inherent in the child care system. It also throws into doubt conventional wisdom that foster placements are preferable to residential ones, given the problems of family contact.

Most of the children admitted to care because of parental illness in Millham and colleagues' study had left care before two years had passed. Those who remained in care tended to have been admitted to the child care system as a result of behavioural problems or abuse or neglect. However, barriers to contact and the strains placed on families in unnatural visiting roles make regular and meaningful contact difficult:

This study has demonstrated that the problems parents and wider families face in maintaining contact with the absent child cannot be comprehended in isolation; that is, understood through a scrutiny of visiting patterns, access restrictions and the distance, location and nature of children's placements in care. Barriers to links between parents and child are also apparent in the child-rescue orientation of much children's legislation, in the control obligations and public accountability of social work, and in the inheritance from the past of punitive and contaminating beliefs on families (Millham *et al.*, 1986: 218).

It is these barriers which contribute to the fear of many ill and disabled parents of coming to the attention of welfare professionals; to their reluctance to seek medical help and support; and ultimately to many of their children becoming or remaining young carers. The paradox is that these fears and the resultant reluctance to seek support exacerbate problems within families and may

increase their likelihood of becoming the subject of punitive professional interventions, including the admission of their children to the child care system - the one thing they fear the most.

Other Consequences of Care

In addition to loss of parent-child contact, care has other negative consequences for the children concerned. At the most extreme level children in care can suffer serious risk of abuse from other children or from their adult carers, as the series of residential child care abuse scandals of the 1980s and 1990s demonstrates (see for example Becker, 1992, 1997). Many children also experience stigma associated with care (see for example Page and Clark, 1977; Stein and Carey, 1986; Buchanan, 1995) and are subjected to discrimination by others, including other children, parents, teachers, prospective employers etc. because it is assumed that they have done something wrong which has resulted in care proceedings. This stigma results in guilt and feelings that they are being punished for misdemeanours. As Page and Clark (1977: 30) state: 'What care has done is to make public the inadequacy of a private family life and to judge its members by implication'. Many young carers also feel stigmatised, sometimes because the nature of their parent's illness results in their being teased or bullied, sometimes because their lives are so different from most of their peers. Additionally, Aldridge and Becker (1993) suggest that some feel they are being punished for something they have unwittingly done wrong. Given this, care may well exacerbate feelings of stigma resulting in children feeling further punished.

Another major problem for children in care is the frequent change of placement. Bilson and Barker (1995) in a study of 631 children looked after under the Children Act found that 20 per cent of those looked after for more than six months had experienced five or more placements. In Buchanan's (1995) study (also post-Children Act), of 45 children in care, the mean number of moves was 4.8. These findings come in spite of an earlier government review of decisions in child care which suggested that many changes of placement were likely but unsatisfactory (DHSS, 1985). Thus care cannot offer the stability which most children require and is, perhaps, no more than a second best option.

A further significant factor is that of education. Aldridge and Becker (1993) offer case studies of young carers threatened with, or fearful of, care proceedings as a result of repeated absence from school. Other research suggests that the educational experiences of young carers are far from acceptable (Dearden and Becker, 1995; Marsden, 1995). However, evidence suggests that the child

care system is more likely to exacerbate rather than relieve such problems. Broad (1997) suggests that young people are under-educated in care and find it difficult to go into further or higher education because of financial constraints, exacerbated by changes in social security such as the introduction of the social fund and the unavailability or limited availability of income support. In Stein and Carey's (1986) study of 45 children leaving care many had missed school, had little interest in education and low attainment, none staying in education beyond the age of 16. A review of residential child care (Department of Health, 1991: 10) echoed this finding, stating:

The educational difficulties that children often bring with them to care may be compounded by their experience of it, with crippling effects on their lives after leaving care.

Buchanan's more recent (1995) study of 12 to 17 year old children looked after included 27 per cent who were in neither school nor employment, again suggesting educational difficulties and low achievement.

Thus, not only are educational problems unlikely to be remedied by admission to the child care system, they may well be exacerbated. This in turn can affect young people's prospects on leaving care. Broad (1997) argues that those leaving care are over-represented in the homeless and unemployed figures, while Kirby (1994), in a study of young people leaving care and becoming homeless, found that most had been excluded or had truanted from school and they had fewer educational qualifications than the national average.

The evidence relating to the incidence of parental ill health as a factor in social work decisions, problems in parent-child contact and the difficulties faced by many children in the child care system (and when they leave it) all suggest that ill or disabled parents are right to be fearful of care proceedings and separation from their children. Although many children looked after as a result of parental illness may be looked after for very short periods of time, for example during the period when a parent (particularly a lone parent) is in hospital and there is no-one else available to care for them, some will have longer-term experiences and the evidence suggests that these are the children who will face the most negative consequences and outcomes of the child care system.

Supporting Ill and Disabled Parents and their Children

Given the fear and anxiety experienced by many ill and disabled parents, and the often negative consequences of care for children, alternative ways need to be found to support parents with poor

health and to try, wherever possible, to keep families together. Where separation is unavoidable - perhaps due to hospitalisation - this must be planned, if at all possible, and parent-child contact maintained throughout. Efforts must be made to ensure that children are enabled to visit their parent in hospital and that parents do not feel their parenting abilities or responsibilities are undermined by separation from their children.

One of the ways in which ill and disabled parents and their children could be supported is to use Section 17 of the Children Act and define such children as children in need. While some groups already acknowledge that *young carers* should be identified as children in need (see for example Family Rights Group, 1991; Children's Rights Development Unit, 1994) we would go one stage further and suggest that *all* children of parents with chronic illnesses or disabilities should be viewed as children who may *potentially* be in need. These children may or may not be young carers, but all may have specific needs because of their family situations, and some may be drawn into caring roles in the absence of outside support. This should in no way undermine disabled parents, but should acknowledge that in families where illness or disability exists there are potential problems and difficulties for both parents and children. It is a matter of good working practice and equal opportunities policy that special needs should be acknowledged:

It is axiomatic that provision should be adequate to meet children's special needs. It should also be recognised that the children of parents or carers who may themselves have disabilities, may have different, and not immediately obvious, needs which should be addressed (Association of Metropolitan Authorities, 1991: 27).

In a study of the implementation of Section 17, Aidgate *et al* (1994) found that local authorities use pre-determined groups of children to identify potential need. These groups include children with disabilities, children who truant, children from homeless families, children in low income families, children in lone parent families and children of unemployed parents. To add children of ill or disabled parents to this list of pre-determined groups should in no way suggest that disabled parents are 'inadequate' parents - any more than are lone parents, poor parents or unemployed parents - but should simply indicate *potential* need. Thus, while many lone parents, unemployed parents and ill parents will manage perfectly well and have few problems, either child-related, family-related, or illness-related, the identification of their children as having potential needs means that, where problems *do* occur, the family as a whole can be helped (see also Aldridge and Becker, 1997). Indeed, Section 17 allows for services to be provided to the *family of* a child in need if it will improve the health and development of that child.

This argument is likely to anger some writers who suggest that 'labelling' the children of disabled parents as 'carers' (and presumably 'children in need') undermines adults as parents (see for example Keith and Morris, 1995; Olsen and Parker, 1997) and are highly critical of the current debate surrounding the provision of services to young carers. What we are suggesting, however, does not involve the further stigmatisation of disabled parents, but the support of all families who have needs, including those where a parent has an illness or disability. While we would agree with Keith and Morris (1995) that disabled people suffer as a consequence of the inadequacy of service provision to them as *disabled people*, we would also suggest that some may suffer because of inadequate services which recognise their needs as *disabled parents*. Indeed, Locker (1983: 163) in a study of people with rheumatoid arthritis, found that 'all the respondents with children had found parenthood problematic in one respect or another and a major source of worry and distress'. Identifying their children as in potential need of support or services - which will promote their health and development - will be of benefit to the family as a whole.

Most models of preventive child care adopt the medical model of primary, secondary and tertiary prevention although as Fuller (1989: 13) indicates:

...distinctions between primary, secondary and tertiary prevention look seductive on paper, and are helpful at an abstract level, but are difficult to sustain in practice.

This is particularly true when discussing the needs of disabled parents and their children, since ideally we would like to prevent several events, such as the admission of these children to care, their rejection or neglect by professionals and the harmful effects of multiple deprivations such as long-term sickness, poverty and isolation. Using the medical model, primary prevention would incorporate the prevention of illness and disability which is unrealistic and unachievable. However, identifying the children of ill parents as children in potential need, whether or *not* they are currently providing care, and providing appropriate services where necessary could be adopted as a primary preventive strategy:

The goal of primary prevention includes both the amelioration of environmental conditions related to problems, and the promotion of social and emotional well being (Sundel and Homan, 1979:514).

Having identified these children as being in need, it is essential that there is communication between different sections within social services departments. Far too often ill and disabled people receive few services, and inter-departmental and inter-agency work and co-operation could ensure that services meet needs and take into account the wider family. For example, social workers in adult services may assess the needs of an ill or disabled person under the NHS and Community Care Act and arrange adequate provision for their needs, without taking into account their needs as a parent or the needs of their children. The provision of services to the family under Section 17 of the Children Act, such as day care for younger children, supervised activities outside school hours for older children, home help etc. can meet the needs of both children and parents. It is essential to look at the whole family, not simply the parent or child in isolation.

If it becomes essential that the child of an ill or disabled person has to be looked after, then this too could be deemed a preventive measure if it succeeds in ultimately preventing *permanent* family breakdown. Aldgate, Pratt and Duggan (1989) suggest that while admission to care has been viewed in the past as a last resort, it can sometimes be desirable and be used in a proactive way. Such relief care could be used for the children of ill parents when treatment is required away from home, or when medical conditions are exacerbated and parents feel too ill to care for their children. Aldgate and colleagues stress the need to include rather than undermine parents in such decisions and that consensus between all parties is essential to ensure that relief care is a positive experience for all involved. Whilst they are referring to regular relief care for families under stress, such a model could be adopted to meet the needs of ill parents, offering occasional rather than regular relief. Such

an arrangement may reduce the negative consequences of care outlined above by acknowledging the barriers to contact experienced by those who are in poor health and ensuring that contact is maintained throughout separations; by listening to the views, experiences and fears of the whole family, acknowledging them and not imposing other 'professional' interpretations and value judgements; and by ensuring that others in health and welfare roles acknowledge the needs of ill people as parents, as well as 'patients' and provide adequate and appropriate services which meet these multi-faceted needs. Arranged appropriately, *temporary* relief care could reduce the fear and anxiety expressed by ill and disabled parents. As Aidgate and colleagues state (1989: 37):

The skill lies in looking at a family's needs in detail, assessing their strengths as well as their weaknesses and taking a pluralist approach to meet those needs. Relief care can then be valued as a positive social work service to prevent long-term family breakdown.

A further measure in meeting the needs of the whole family would be for professionals in health and social welfare to listen to *all* members of the family when making decisions. In the case of Cathy and Sean, mentioned earlier (Dearden and Becker, 1995), they were aware of their mother's deteriorating mental health but their observations and fears were ignored or dismissed by professionals. When their mother's mental state deteriorated further they were removed from the family home and taken into care, where they still remained two years later. Had their views been taken seriously, rather than dismissed, it is possible, but by no means certain, that the situation may have been avoided. Many children who live with ill or disabled parents will have some knowledge of the medical condition involved and will be in a position to contribute to discussions regarding support for the family - their views should be considered as active family members rather than put aside because of their age and perceived dependence.

Poor health may be part of a complex web of social disadvantage because of the poverty and deprivation so often associated with it. Multiple deprivation is common in children admitted to the child care system and this has led to the punitive way in which care has been perceived in the past and continues to be perceived today, particularly in poorer households (Becker, 1997). Disabled parents are often aware of this:

Poverty may also call into question the adequacy of disabled parents and their spouses since it may prevent or make it more difficult for them to meet conventional criteria defining good parenthood. Parents are held responsible for providing for the material needs of their children, in particular, for making sure that they are adequately fed and adequately dressed

(Locker, 1983: 129).

Of course I had a fear. I tell you, one big fear I had and it was horrific. I wouldn't accept any help from the services, the likes of home help, I was terrified if they took her off me. I was terrified in case they'd say, 'Because of your illness, because of everything, you're not capable of looking after her, you're not', and I daren't say anything. I daren't let them know how I was feeling, or how she was feeling (Mrs Hunter, quoted in Aldridge and Becker, 1994: 10).

Disabled people hide it because they're frightened of losing their kids. I didn't contact any professionals because of that (Mrs Barker, *ibid.*).

It is imperative that professionals make improved efforts to reduce fear of social service provision and support disabled parents rather than alienate them. The Children Act has been designed to try and alleviate some fears by acknowledging parental responsibility and assuming parent-child contact will occur, but some of the studies cited above suggest that the potential benefits of the Act have yet to filter down to users of services.

One of the biggest battles facing welfare professionals in being proactive in supporting ill and disabled parents and others, is the lack of funding available and the prioritising of need in a budget constrained service. The political consensus on a mixed economy of welfare and the need for 'personal responsibility' has legitimised a move from collective solutions to social ills, to the private or individual resolution of need. The residualisation of state welfare, according to Hardiker, Exton and Barker (1991), is likely to lead to only tertiary preventive measures for those in imminent danger, the emphasis being on statutory obligations with task-centred, short-term interventions. The support of parents with poor health requires much more primary and secondary preventive work with an emphasis on family support rather than punishment. Unless changes in policy and ideology are forthcoming, and are matched by adequate funding, ill and disabled parents are likely to continue to receive poorly planned crisis intervention in a punitive manner and will have every reason to be fearful of professional intervention. Moreover, as this review of the research indicates, their children will have a high vulnerability to entering the care system, with all the inherent dangers and outcomes associated with it.

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