

Prevention and Intervention: Young Carers and their Families

A report prepared for the
Calouste Gulbenkian Foundation

by Jo Aldridge 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.

Prevention and Intervention - Young Carers and their Families

Introduction

Following the recent trend in tracing the experiential conditions of children who care (Bilsborrow, 1992; Meredith, 1992; Aldridge and Becker, 1993, 1994; Dearden and Becker, 1995a) and the implementation of policies and support services for these children it is perhaps time to shift the focus of attention away from the conditions of childhood where child caring prevails to consider methods of *preventing* children from becoming carers in the first instance - of arresting the processes that lead children into caring when such caring can all too often have a restrictive impact on their lives (Aldridge and Becker, 1993, 1994).

We do not need to research further the lived experiences and conditions of young carers (and those children who do not have to care) in order to know and understand the effects of caring on children. This work has already been done and consistent patterns have emerged that underline how caring impinges on children's lives in diverse ways: socially, emotionally, educationally (Bilsborrow, 1992; Meredith, 1992; Aldridge and Becker, 1993; Dearden and Becker, 1995a). It is thus timely that we move away from a *primary* focus on these children's experiences and needs to consider preventive strategies that may facilitate children a greater freedom to lead lives that are unfettered by substantial or primary caring responsibilities.

However, we must stress that in emphasising the need for looking at preventive measures in relation to young carers we do not wish to underplay the work that has been done and is currently underway to provide support services for children who *are* carers. On the contrary, we would wish to champion the work of the many welfare professionals, voluntary groups and agencies who are presently working to assist young carers and hope that they will continue to do so.

At this stage any strategies for prevention in respect of young carers will inevitably be both embryonic and speculative in nature, and one of the purposes of this article is to generate a dialogue which focuses on intervention and prevention between those professionals working in the child welfare services. Such a dialogue should consider the potential for preventive

programmes in the young carers' debate as well as the probable effectiveness of preventive measures both theoretically and practically. In theory preventive strategies are clearly aspirational. In practice they may prove problematic for various reasons, especially those primary programmes aimed at preventing young caring from becoming a social reality. We will discuss this in some detail later.

Young Carers and Young Caring in Context

In considering preventive strategies for young carers we are better placed today than we would have been only a few years ago. Until the early 1990s, when the experiences and conditions of young carers were highlighted by researchers and campaign workers alike, young carers remained sequestered within families who were often reluctant to seek help or support from statutory (or voluntary) agencies. The issue of young caring had failed to capture the interest of both policy makers and those welfare professionals working in the field who should have been supporting these children. However, we would argue that by its very emergence as a subject for research and debate, and its subsequent development both theoretically and practically, preventive action is, to a large degree, already underway. The recent focus on young carers by academics and policy makers alike has resulted in raising awareness to the issue. Furthermore, organisations such as the Carers National Association, Crossroads and Barnardos have likewise played their part in a nationwide awareness raising campaign which has been closely monitored by an attentive national media.

On a practical level the growing interest in young carers' issues has not only emphasised the need for support services and generated public interest, but more significantly it has helped to change policy. Previously, the specific needs of children who care were covered neither by the NHS and Community Care Act nor the Children Act. However, as a result of research strategies and extensive campaigning young carers have been included in the Carers (Recognition and Services) Act which was implemented in April 1996.

A wide range of support services have since been set up across the country from respite care schemes to befriending projects (see Dearden and Becker, 1995b). Furthermore, and significantly, the young carers debate has alerted professionals both to the reality of the young caring experience and the

potential for it. The increasing focus on young carers' issues has served to highlight within the child welfare services the many scenarios and circumstances in which young caring is founded and maintained.

Prevention and Intervention Strategies

We believe the formulation of a preventive strategy for young carers would, *in theory*, achieve three fundamental objectives: it would help prevent growing numbers of children who need support as carers; it would benefit disabled or ill parents and families as a whole; and it would relieve the financial burden on support services presently in place to help children who are already caring.

However, whilst advocating the need for preventive programmes in relation to young carers' issues we are aware that although the notion of preventive strategies on a more general level in child welfare has attracted growing interest over more recent years (see, for example, Sundel and Homan, 1979), it has also generated considerable debate about the actual *effectiveness* of preventive strategies. For example, in his discussion of the problems and possibilities for preventive measures in social work, Fuller (1989) argues:

“Much discussion of the concept of prevention in social work is at the level of rhetoric, often of an ‘if only’ kind, and even of mythology. The preventive aspiration would suggest that if only problems could be tackled in the right way at an appropriate stage, they could be ‘nipped in the bud’ and prevented from reaching a stage of crisis” (p. 9).

Although preventive measures in the child welfare services are clearly desirous in practice, on the whole specific guidelines for implementation are often wanting. Furthermore it is often difficult to expedite theoretical models of prevention in a practical setting. From a social work perspective, for example Fuller (1989, p.9) argues: ‘In the first place problems experienced by the clients of social work come neither singly nor neatly compartmentalised. Clients are typically at different stages of involvement with a number of different agencies and their multiple problems are often interlinked’.

Although, as we have said, any proposed programme of prevention in respect of young carers would be both embryonic and speculative at this juncture, such measures are necessary if we are to protect children who are essentially vulnerable - as Sundel and Homan (1979, p. 519) argue: ‘If child welfare

services were perceived within a framework directed toward the goal of prevention, they might be more likely to serve as a means to achieve the ultimate goal of a stable, nurturing environment for children'. And we would argue that a strategic preventive programme aimed at young carers and their families (certainly secondary and tertiary measures - see below) may in many respects be less problematic than trying to define and implement preventive strategies for a more broad based child welfare service. We already know the causal factors that lead children into providing care and these are that their parents have physical or mental impairments, and that both parents and children are inadequately supported for a number of reasons (Aldridge and Becker, 1993, 1994). In other words, the causes of child caring are to be found in the complex interplay between medical *and* social determinants, not least the 'disabling' barriers engendered in much contemporary social welfare and social service policy, organization and practice. Many welfare professionals continue to ignore the needs and rights of children and parents in families where parental illness or disability is present.

Prevention and Intervention for Young Carers and their Families

A health care perspective on prevention has emphasised the three phases of intervention as primary, secondary and tertiary measures. Social work authors have also been interested in exploring the potential effectiveness of such interventions in respect of the social services. Hardiker, Exton and Barker (1991) for example suggest the three phases of prevention, as applied to social work practice, would involve implementing measures that prevent client status, as a *primary* preventive measure; a *secondary* step would involve ensuring that those who had already acquired client status would return, as soon as possible, with appropriate and effective intervention, to non-client status; and a *tertiary* strategy would focus on risk cases - where families are in crisis and children are at high risk of being taken into care. A fourth stage intervention has also been suggested which is the quaternary level - where the emphasis is on rehabilitation and minimising the damage when a child has already been admitted into care.

We would suggest that the three phase preventive model as applied to children whose parents are ill or disabled would involve, as a *primary* offensive, strategies that prevent children being drawn into caring roles in the first instance; a *secondary* intervention would mean addressing the family's

circumstances and needs when children have already adopted caring duties in the home, but would perhaps be able, with the input of appropriate services and support, to return to non-carer status; and a *tertiary* intervention would involve supporting those children who are already caring, and who may be in crisis, from being separated from their families. There would be some crossover in the secondary and tertiary phases as an objective of both interventions would be to prevent children who are already caring from being drawn further into heavier and longer term commitments which could have a restrictive impact on their future lives, as children and adults.

In respect of those children who are already caring, preventive strategies for young carers are patent, and many services are already operational to deal effectively with the needs of these children and their families. Such services include respite care schemes, befriending projects, self help groups, family counselling and advocacy etc. However, such schemes often run independently of local authority departments and are often concerned with treatment as opposed to prevention. Thus, they may offer befriending, respite care or counselling to the young carer, concentrating on *relieving* some of the strains of caring on children as opposed to *reducing* the potential for caring to become established or long term. Although such services are welcome (especially to the young carers who make use of them there and then), other support services (ones which run in collaboration with other agencies and services) should aim to remove long term caring commitments among these children. These might include, for example, the input of services for ill or disabled parents, family counselling, respite care etc.

In respect of *primary* interventions, however, we have to consider seriously whether any form of intervention will ever successfully prevent some parental dependency on children for care. Indeed, to some extent we could argue that the very fact we cannot prevent chronic illness or disability among all parents means we cannot prevent some of their children from caring *in some form*. In theory we can highlight measures which would prevent children whose parents are chronically sick or disabled from having to care in the first instance. In practice we may only achieve a reduction in the level of care provided by children and perhaps lessen the potentially restrictive aspect of caring on children's educational and social lives. We may also be able to avert crises, thus preventing familial breakdown or separation.

Thus, a *primary* prevention would inevitably be aspirational in that its focus would be on preventing young caring from becoming a social reality. *Secondary* and *tertiary* interventions would then perhaps be more realistic objectives in that the emphasis would be on reducing children's caring responsibilities, forestalling long term caring commitments by children, lessening the restrictive impacts of caring and preventing crises and family separations.

In light of this, in order to define an expansive preventive strategy for young carers, and those vulnerable to providing care, it would be necessary to adopt a composite perspective. A combination of measures would contribute to the advancement of a primary preventive strategy as well as being useful in reinforcing and maintaining secondary and tertiary interventions. Such measures would rely heavily on the responsibilities of welfare professionals to be more vigilant for the potential of child caring; to adopt a more family centric approach (and to include children in their needs assessments); to acknowledge children's rights; to disseminate information; and to offer appropriate services. It is to these issues that we turn now, as well as to a discussion about the role of independent living and progressive services for ill and disabled adults in the prevention debate.

The need for vigilance

Considering the history of neglect of young carers it is essential that welfare agencies and their staff are aware both of the *reality* of young caring and the *potential* for it in families where parental illness or disability is present. It is to be hoped that there is now a growing consciousness among welfare professionals in respect of young carers and, as we have already suggested, that the continuation of neglect of children who care (as well as those who *could* care in the future) has to some extent been arrested. A recent challenge to the young carers debate from certain disability authors has suggested that one of the negative consequences of the debate has been that welfare professionals now have their 'young carers spectacles on' (Parker and Olsen, 1995, p. 70) in their dealings with families. We would argue that far from this being a counterproductive response by the welfare services, it can only benefit young carers and their families and we would hope for the *continued* vigilance and responsiveness of professionals in this respect.

Indeed, we would argue that if we can aspire at all to the prevention of young caring as a social reality it is essential that some form of what we might call beneficent observation is carried out by those professionals involved with vulnerable families whose circumstances may be either uncertain, in transition or even in crisis (when children might be called on to care if support services failed or new and different needs had arisen). This means that professionals have to take on the responsibility of monitoring for change themselves or improve their communications with other professionals who may have further involvement with vulnerable families (it was clear from our research that many agencies were unaware of the involvement of other welfare professionals in families, see Aldridge and Becker, 1993, 1994). GPs, for example, would be ideally placed in this respect in that they would know a patient's circumstances and where parental illness/ disability was present in a family they would possibly be aware of changes in family circumstances (i.e. unemployment, separation or divorce) and the onset of new stresses or anxieties.

In relation to any changes in *children's* behavioural patterns or stress levels, teachers and educational welfare officers would be ideally placed to monitor for change. However, such professionals are not always privy to family circumstances and are often deliberately kept in the dark by children who don't want to be identified as 'different' in any way (Aldridge and Becker, 1993). Indeed, we found that often where children are already caring, family members are reluctant to reveal their home circumstances to anyone outside the family for fear of the impacts of any professional or community intervention. Although we must respect their right to privacy on the one hand, we must also strive to *inform* them of the availability of alternative support services in an empathic and benign manner. Although as Hardiker, Exton and Barker (1991) have rightly pointed out 'intervention is not always benign' (p 349), we must endeavour to make it so. And monitoring families for change and signs of crisis need not be an ominous exercise. Hardiker, Exton and Barker (ibid.) for example, highlight the importance and value of family centres in their multifarious forms as a way of preventing problems and monitoring families: 'Family centres may take many forms, from a primary developmental role to an institutional or even a residual one, providing supplementary care, teaching parents better parenting, *monitoring children's progress and providing increased professional surveillance of vulnerable and disadvantaged families*' (p. 355, our emphasis).

A Family approach

It is clear both from our research findings (Aldridge and Becker, 1993) and those of other authors in the field (for example, Meredith, 1991) that where children are caring families are often reluctant to seek help for fear of aggressive intervention strategies by welfare professionals that may lead to care and supervision orders and familial separation. Indeed, Meredith has suggested (1991, p 9) that such fears are far from ungrounded: 'At present people often fear that a social worker's response will be to put their child into care and sadly it is apparent that the option of care proceedings is used, or threatened, much too early'.

Clearly, in order to remove this fear and in order to prevent the continued sequestration of children who care as well as prevent child caring from becoming a family 'norm', welfare professionals must make approaches that do not threaten the fabric of family lives. Thus, it is essential that a shift in focus from one which concentrates simply on the needs of the ill or disabled adult in the home to one which includes the needs of all family members, *including the children*, is necessary. As Hardiker, Exton and Barker (1991) suggest, it is imperative that family integrity is maintained at all times and that preventive intervention is both empathic and sensitively executed:

"Given the inescapable rescue and control functions of social work agencies, client status may lead to increasing interference in their lives, particularly in situations of risk and vulnerability. Thus a prime objective at every stage is to prevent the necessity for increasingly intrusive interventions, thereby maintaining autonomy and family integrity" (p. 349).

This shift of emphasis is echoed by other authors who are calling for a *family* approach to welfare provision as opposed to focusing simply on individuals and their specific problems. For example, Fiedler, Edwards and Smith (Department of Health, 1995) have stressed the importance of adopting a family perspective when considering the needs of young carers. They make reference to the Chief Inspector's letter to directors of social services departments (C1(95)12):

"where the disabled person is a parent, it is essential that the community care assessment focuses on the family and considers how to support the parent and recognise the needs of any young carers" (p. 24).

The emphasis on the needs of the family also finds its parallels in the government's latest call for a 'refocusing' strategy, from protection to prevention. Talking at a conference hosted by the Department of Health (26 Sept, 1996), Health Minister Simon Burns said:

"Research tells us that children are generally well protected when there are serious child abuse concerns. The challenge for us all now is to extend that successful collaboration to wider work in support of children *and their families in need.*" (our emphasis).

The key elements of this refocusing strategy are that services should be both needs-led and driven by their outcomes for children; and there should be a community based approach to child protection and family support.

In terms of implementing a preventive strategy that encapsulates the needs of the whole family, it is essential children are included in needs assessments. Under the NHS and Community Care Act 1990 people who are disabled have a right to a needs assessment and to the provision of support services. The Children Act 1989, (Section 17, on children in need) allows for service provision to the *family* if the child is considered to be in need (Dearden and Becker, 1997). Aldgate *et al.* (1994) suggest that local authorities use pre-determined groups when identifying children in need. For example, those from low income families, those with special educational needs, those excluded from school etc. We would suggest that children of long-term ill or disabled parents are included as a pre-determined group of potential children in need. This would facilitate the early provision of services to the whole family, following a family needs assessment, thereby preventing children from caring or from undertaking long term and potentially restrictive caring duties.

In highlighting the need for a programme of prevention for children who are vulnerable to caring we are saying that restrictive child caring is unacceptable. Although we would argue that child caring is an inevitable social reality (as we cannot prevent either chronic parental illness or disability, or ensure that welfare organizations operate in a truly empowering and demand-led way), in emphasising a family approach as a preventive tool we are stressing the importance of family autonomy, and family rights. Thus, where parents and children want some form of caring by children to continue

(see Aldridge and Becker, 1993, 1994) we should not be intervening aggressively to ensure that children return to non-carer status. From our research it was clear that often where child caring was a preferred option in families it was often thus because of the *established* nature of the caring relationship i.e. some children had been caring for so long that they (and their parents) were reluctant to relinquish the role to an 'outsider'. Therefore, any primary preventive strategies should aim to remove the need for these established caring practices in families by the provision of appropriate support services for the whole family. Secondary and tertiary interventions, whilst recognising the established nature of child caring in certain families, should attempt to re-establish children as non-carers, remove the heavier burdens of care on children, lessen the restrictive impacts of caring and try to avert crises arising.

Of course, where those families feel they have no choice but to involve their children in caring - where children are forced into the role, 'elected' or 'socialised' into it because they feel there is no alternative (and thus child caring has become an established family routine), that is, they have little or no outside support and don't know how to access it, then this is where a primary preventive strategy could be very effective in that it would simply involve a bombardment of support options and information for families at the onset of parental illness or disability, presented in such a way as to be helpful and enabling rather than overwhelming and debilitating.

Children's rights

We believe that children who care have rights as children and as carers (see Aldridge and Becker, 1993). Regardless of the ongoing debate about children's access to rights as well as the recent criticism of our stance on children's rights from those authors far more interested in the rights and needs of disabled adults (see Parker and Olsen, 1995; Morris and Keith, 1995), it is clear that children who care (as well as those children who are potential young carers, or indeed *any* children) have rights enshrined by legislation, not least the UN Convention on the Rights of the Child (Dearden and Becker, 1997). These would include the right not to be ignored by the welfare services and to be included in discussions if that is what they and their families want. They also have a right to a secure and stable childhood environment which allows them growth and integrity, and as we now know, caring responsibilities can restrict children's personal growth in this way.

Furthermore, ill or disabled parents have a right to alternative professionalised forms of care provision. Indeed, we would argue that if we are to prevent children from being drawn into caring roles at all it is essential that their right to be included in family discussions about needs assessments, service provision etc. is acknowledged and affected. In relation to the medical services, for example, it has been suggested that it helps family cohesion if children are included in discussions and plans about coping with and managing family illness/ disability from diagnosis to treatment and rehabilitation (see Sturges, 1978).

Thus, if children whose parents are ill or disabled are included in consultations with welfare professionals they may at least be prevented from being drawn *unwittingly* into caring roles and may seek help or support if caring becomes their only option. If they and their families are aware of the caring choices available to them and have access to other services, benefits etc. they may also be more assertive in presenting their needs to empathic and responsive professionals.

Professionals should also be aware that children may need support for themselves either in the form of information, discussion or personal counselling relating to coping strategies in respect of the parental condition. Children need to be allowed the opportunity to discuss their anxieties and concerns in this respect.

Information

Furthermore, the same could also be true if these families have easy access to information. Our research has suggested (Aldridge and Becker, 1993) that families have urgent needs for information about a wide range of topics from domestic and social support to information about benefits, medical assistance and voluntary forms of provision. Additionally, children have the right under the UN Convention to have their information needs met. We would argue that it would also be profitable if families were informed (appropriately and strategically) about some of the issues surrounding young caring, for example when and how it can occur and why dependence on children for caring should be avoided. Although we are not suggesting that welfare professionals transform themselves into what we might call virtuoso informants, it is perhaps not unreasonable to expect them to be able to offer either some form of personal assistance in relation to information provision, or to refer families

to alternative information sources if they do not have the answers to questions themselves. Although there may be, as Fuller (1989) argued, a number of different agencies involved with one client at various stages, and a client's problems may be interlinked, this should not be seen as an obstacle to support in terms of the information needs of a client, if all those professionals involved volunteer appropriate information. Over compensation in this respect would be preferable to a situation where nominal or partial advice is offered leaving families only further confused.

The dissemination of information should of course extend to children who, in many respects, are all too often left out of the information equation (see Aldridge and Becker, 1993) . Although we are not suggesting that providing information to children about services, medical conditions etc. will *on its own* prevent them from caring, it will go some way to preventing the isolation and seclusion of children who care and may to some extent prevent them from either continuing to care unaided or undertaking extensive and intensive caring roles in the first place. It was clear from our research, for example, (ibid.) that children were woefully uninformed not only about where to go for help or support for themselves and their families but also about the medical condition they were helping to manage. In most cases the children knew so little about the medical condition of their parent that they had invented their own versions of diagnosis, prognosis and the possible consequences in respect of their own health. For example, in the case of those parents with Multiple Sclerosis (MS), none of the children who were caring for their parents had been informed about the condition and its effects, or how it would or could affect them (both in relation to their own physiology and in terms of care management). Hence one girl had assumed that MS was a contractible disease that she would catch from her mother at some point. She thus saw in her mother, for whom she was caring, her own dependent fate at some future point.

Even where those professionals (for example, GPs, social workers) knew a child was heavily involved in caring at home they continued to ignore the child's needs and overlook their contributions to caring in families. Significantly, when information was offered, as it was for example in the case of Debra (Aldridge and Becker, 1993), this proved to be a useful therapeutic tool. Debra had cared for her mother who had Huntington's Disease (HD) and because of the disease's serious genetic implications (i.e. that Debra had a

one in two chance of developing the disease herself) she had access to a HD key worker (albeit after she had finished physically caring, when her mother was hospitalised). However, although we could not assume that information and HD support during her mother's illness on its own would have prevented Debra from caring, a key worker such as she was assigned certainly helped her confront many issues she had refused to face when she was caring for her mother in relation to the disease itself and its consequences for Debra's own future health.

Support and information such as Debra was offered would arguably also relieve some of the pressures on parents to discuss medical issues with their children. It was clear from our research that parents are often reluctant to discuss their illness/ disability (Aldridge and Becker, 1994) or are sometimes equally unsure of their own diagnosis and prognosis and thus often don't feel qualified to tutor their children on the condition. A number of medical agencies and societies now provide child-oriented information about medical conditions. For example, the Parkinson's Disease Society have produced information about the disease which is specifically aimed at children (Reading, 1995a, 1995b). This came about as a result of research into children of parent's with Parkinsons Disease (Grimshaw, 1995).

Prevention and Intervention in Practice

Collectively, factors such as increased professional vigilance and responsiveness, adopting a family centric approach, disseminating information, referrals, counselling etc. may go some way towards helping families cope in situations when they feel they have no choice but to involve their children in caring. In this way we may have the beginnings of a primary intervention strategy which could obviate the need for some children to take on caring responsibilities in the home. Collectively, these measures, as well as the continued provision of those services already aimed at young carers and their families, make up a primary, secondary and tertiary programme of prevention and intervention (this is illustrated in Figure 1). To further illustrate how such a preventive strategy could work in practice we can look at a case study from our original research (Aldridge and Becker, 1993, 1994) and highlight the points at which intervention could have helped prevent parental 'dependency' as well as alleviate the strains on a family already under great stress.

Mrs Hunter was diagnosed as having Multiple Sclerosis soon after the sudden death of her husband leaving her to bring up their daughter, Alison. Alison was only nine years old when she began caring for her mother. She continued to care in an atmosphere of fear and isolation for several years.

Mrs Hunter:

“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 [my daughter] 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” (Aldridge and Becker, 1994, p. v).

Alison was what we have termed ‘socialised’ into care and continued to care unaided and in seclusion because both Alison and her mother were afraid that any outside intervention would mean they would be separated. Social services practice has taught us that this was not an exaggerated response (see Meredith, 1991).

Furthermore, partly as a result of Mrs Hunter’s reluctance to seek help through fear of intervention and partly because of the response of the welfare services when she did eventually ask for support (when she thought her daughter would be considered old enough to stay with her) Alison’s needs went unrecognised. The only point at which Alison’s contribution to caring was acknowledged was, perversely, when community care assistance was withdrawn because she was deemed ‘old enough to care’. Even the family GP overlooked Alison’s needs both at the onset of her mother’s condition and at the time of her father’s death. Theoretically speaking, a primary preventive strategy would have been difficult to implement in respect of this family because of the level of crisis involved - the sudden loss of a parent (as well as the main income) and the sudden onset of a degenerative condition in the remaining parent - and because of the family’s resistance to outside intervention. Furthermore, Mrs Hunter’s circumstances had changed suddenly from a well, two parent family to a lone parent with a progressive illness, thus increasing the pressure on Alison to fulfil the main caring role.

However, a secondary intervention such as strategic and appropriate counselling (for both Alison and her mother), the provision of information relating to services, benefits and care provision, as well as the practical application of services would have relieved many of the stresses placed on this family. Although these measures wouldn't have prevented Alison from caring altogether (support services simply were not available through the night and at those times when Mrs Hunter needed extra care and support) they would undoubtedly have reduced the level of care undertaken as well as lessen the restrictive impact of caring on Alison's life.

Although preventive measures in the young carers' debate may not be as complex or problematic in terms of implementation as in other areas of child welfare, in the current economic climate they may have to take second place to mainstream child welfare services. We have said that preventive measures for young carers are as yet both embryonic and speculative and they may have to remain so if the pressures on the welfare services dictate that, in terms of prioritising needs, preventive strategies become subordinate to other more conventional services. Sundel and Homan (1979) have themselves argued that we need to consider the legitimate role of prevention in welfare provision when resources are dwindling and needs are increasing. It is in such a climate they say that preventive programmes are compromised: 'Serious attempts to design and implement preventive programs have often been short-lived because of the pressing demand for conventional social services' (p. 510).

Independent Living and Progressive Services for Ill and Disabled Adults

Indeed, the constant demands placed on an already over-stretched and under resourced welfare service is one argument against the strategy of prevention which has been proposed by some disability authors in relation to young carers (see Parker and Olsen, 1995; Morris and Keith, 1995; Olsen and Parker, 1997). These writers have suggested that providing independent living and comprehensive support services for disabled adults will prevent children from having to care:

"The best way of meeting the needs of young carers is not by creating new welfare categories, but rather by meeting the daily living needs of their parents" (Parker and Olsen, 1995, p.72).

We would suggest that such an argument takes us further into the realm of rhetoric and 'if onlys' (see Fuller, 1989). It seems too simplistic an argument, in preventive terms, to suggest that comprehensive support for disabled parents will prevent their children from caring when the promise of such extensive support remains unfulfilled, despite disabled people's 'rights'. Furthermore, how long will it be before this 'ideal world' scenario is realised, and what will happen to disabled parents and their children in the meantime? Our argument is not that comprehensive disability support services will never be available for all so we must not aspire to them, rather while we are waiting for a utopian or enabling welfare service for disabled people something has to be done to help those families who need assistance now. Thus, both because we cannot prevent parental illness or disability and because comprehensive services for these parents remain unfulfilled, we cannot rely on a primary preventive strategy to avert the need for parental dependency on children for care.

Therefore, the need for intervention will inevitably focus on those secondary and tertiary measures to prevent the further neglect of families, the isolation of children who are already caring, and to avert some of the more restrictive effects of caring on children as well as prevent crises which might lead to familial separation. Although it is important to pursue the *ideals* of prevention for those children who are vulnerable to providing care in families where parental illness/ disability is present, we have to ensure the *practice* of intervention for those children who are already caring.

Disabled people and their young carers are both subject to disabling barriers (Becker, 1995, p. 19). We recognise that in an ideal world where the voluntary and statutory support services are willing and able to provide extensive or unlimited support, the role of young carers would be greatly reduced. But we also recognise unpalatable current political and economic realities and that in an increasingly pressurised and residual welfare system, in the context of economic recession, uncertainty and charges for social care, family carers are going to be expected to continue their support. We do not want children who are having to fulfil this role to continue to do so unsupported while waiting for comprehensive support services for their parents.

In terms of prevention we would, in theory, support an independent living solution to parental 'dependency' where disabled people exercise full choice

and control in their parenting activities, but we are also all too conscious of the lack of choice that disabled parents and their children often have in relation to care provision.

Morris (1995, p. 56) has argued:

“Professionals, campaigners and researchers alike should focus more clearly on what needs to be done to prevent parents having to rely on their children for such tasks. In particular, they should focus on how disabled people can access the clear rights they already have under existing legislation to practical assistance, aids, adaptations and equipment.”

However, we must stress again that although fulfilling disabled people's needs and acknowledging their right to practical assistance etc. would to some extent remove the need for some children to care some of the time, our evidence suggests (Aldridge and Becker, 1993) that many children are providing levels of support that the welfare services *under present economic and political conditions* could not fulfil.

To return to our case study for example, when Mrs Hunter (Aldridge and Becker, 1994) requested occupational therapy and specific adaptations and equipment it was a long, hard struggle and she found that due to limited resources she often received only what the welfare services could offer, as opposed to what she actually wanted:

“I told the OT [occupational therapist] what I needed done, but they twist words round, they say things like, ‘well it’s what you want’. It isn’t what I want, it’s what I’ve been lumbered with... The home help system as it is is far too stretched to do any good, or to get any sense out of it, they’ve got far too many clients” (Aldridge and Becker, 1993, p.7).

Furthermore, when we conducted our research many of the young carers were caring through the night and would continue to do so as the availability of night sitters, for example, was extremely limited - three members of staff were available to cover the whole of the Nottingham city area.

Thus, the reality is that a primary preventive programme for those children whose parents are ill or disabled may be less effective (because of increasing

financial demands on under-resourced services) than secondary and tertiary strategies that seek to alleviate the strains on those children who are already caring. Having said that, the *ideal* of a primary preventive strategy is one which we should aspire to.

Conclusion

Despite the best efforts of any proposed primary preventive strategy for children who may be vulnerable to providing care for their ill or disabled parents, there will always be those families who are forced into some reliance on their children for care provision. Some families may resist professional intervention at all costs; others will not have all their needs met due to dwindling resources and increasing pressures on already over-stretched services, or because of poor practice within such organizations; others still will need to rely on children for care management at certain times or for specific duties when outside support simply isn't available. Then there will be families who will remain suspicious and fearful of outside intervention despite the best efforts of well-intentioned welfare professionals. In these scenarios, the demand for intervention strategies will inevitably fall on secondary and tertiary measures to help those families whose children are already providing care and who need some form of support.

Disability authors such as Parker and Olsen, Morris and Keith, who have focused primarily on the rights and needs of disabled adults, have emphasised the need to look at the *primary* prevention of parental dependence on children for care and have suggested that this takes precedence over supporting children who are already providing care: 'Finding ways of stopping it happening... has a higher strategic priority than finding ways of making it easier for such unacceptable situations to continue' (Olsen and Parker, 1997, p. 131).

We agree that a preventive strategy for young carers is necessary. However, in light of the issues highlighted here - the inability to prevent illness/ disability, the fact that some families slip through the net and resist support (see Aldridge and Becker, 1994), economic constraints that mean comprehensive services for disabled parents are unfulfilled - primary strategies alone will neither suffice nor should they be prioritised in terms of a three phase preventive model. Furthermore, and significantly, it is possible

that any preventive programmes will have to fill a subordinate position in terms of the overall priorities of the welfare services. It would therefore be both unhelpful and unrealistic to suggest primary preventive strategies take precedence over those secondary and tertiary procedures, some of which are already in place to alleviate the stresses and restrictive impacts of caring on children and their families. We would argue that child caring will either be a public or private reality whatever support is offered either to ill or disabled parents, or their children. What is needed is a preventive strategy which incorporates both *prevention* and *intervention* and which ensures children and their families are protected and supported.

Figure 1. A Preventive Model for Young Carers and their Families

	Primary Prevention	Secondary Prevention	Tertiary Prevention
AIM	To prevent the onset of caring among children whose parents are ill/ disabled	To return children already caring to non-carer status and prevent long-term (and potentially restrictive) caring commitments. To relieve strains on young carers and their families	To prevent crises leading to family separation and to prevent breakdown.
ACTION	Awareness-raising 'Whole family' approach Ongoing monitoring of families Increased multi-agency activity Maximise income (benefits) Input of services Dissemination of information	'Whole family' approach Ongoing monitoring of families Increased multi-agency activity Input of services Dissemination of information	'Whole family' approach Crisis management Input of services
SERVICES FOR ILL/ DISABLED ADULTS	Respite care; night sitters; home care (Occupational Therapy, meals on wheels, day care); direct payments; voluntary sector support groups; welfare rights advice etc.	Respite care; night sitters; home care (Occupational Therapy, meals on wheels, day care); direct payments; voluntary sector support groups; welfare rights advice etc.	Respite care; night sitters; home care (Occupational Therapy, meals on wheels, day care); direct payments; voluntary sector support groups; welfare rights advice etc.
SERVICES FOR CHILDREN	Counselling; advocacy. Family therapy; information provision; financial support; self-help groups; welfare rights advice.	Counselling; advocacy. Services for young carers; befriending; drop-in centres; young carers' groups; information provision; financial support; self-help group; welfare rights advice.	Counselling; advocacy. Services for young carers; befriending; drop-in centres; young carers' groups; information provision; financial support; self-help groups; welfare rights advice.

NOTE: Many services can be provided at the primary, secondary or tertiary level. It is the aim of the service provision and its timing which determines whether it is a primary, secondary or tertiary strategy.

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