Missing persons and missing helpers: young carers, the family and the faith community.

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Citation: BONNEY, R. and BECKER, S., 1995. Missing persons and missing helpers: young carers, the family and the faith community. Loughborough, Leics. : Loughborough University

Metadata Record: https://dspace.lboro.ac.uk/2134/630

Publisher: © Young Carers Research Group

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A discussion paper by Richard Bonney with Saul Becker
Prepared for the Family Life Committee, Diocese of Leicester
First published August 1995 by

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Designed by the Young Carers Research Group.
Typeset and printed by Backhurst and Taylor Ltd., Nottingham.

British Library Cataloguing-in-Publication Data.
A catalogue record for this book is available from the British Library.

ISBN 0 907274 15 3

Acknowledgements
Our thanks to Jo Aldridge who conducted the fieldwork which informed much of this
report, and for her helpful comments on an early draft of the paper and to Betty Newton
for her helpful suggestions. Particular thanks to Chris Dearden for all her help with an
erlier version of this paper. We are also grateful to the Family Life Committee for their
contribution towards the printing costs of this report.

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Missing Persons and Missing Helpers
Young Carers, the Family and the Faith Community

A discussion paper by Richard Bonney with Saul Becker

Introduction

Young carers are children and young people whose lives are restricted because they provide care for a family member. This is usually a parent but may also be a grandparent, sibling or other family member. The exact number of young carers is unknown, but recent secondary analysis of the 1985 General Household Survey data on carers’ suggests that 17 per cent, or over 200,000 carers aged 35 or under, began caring before the age of 16. These figures do not indicate the intensity of caring roles, nor do they indicate the geographic distribution of young carers, but localised research projects and service providers have identified young carers in many parts of the country.

In this paper we suggest that many young carers lack support, both informal, family support and formal, professional support. This lack of support leads to them experiencing, in effect, ‘missing persons’ and ‘missing helpers’ in their lives as carers. The position of young carers has been ignored, in the past, by members of their families; by the community at large; and by professionals working in the statutory sector, in the areas of education, health and social services. We have not succeeded in caring for the carers. The Church and other faith communities must be included among the missing persons and missing helpers.

Do we care? Are we prepared to be part of the community which supports the best endeavours and strengths of young carers? Do we allow ourselves the self-indulgence of judging others who are often ‘elected’ to duties they perhaps would not willingly have chosen at their age, and which distinguish them from their peer group? Is there not a legitimate place for anger and outrage that, in some cases, relatively simple needs for respite care and befriending have not been, and are not being, met by professionals and social care agencies?

We can understand our relationship to our family by drawing a simple family tree. For Katherine, aged six, some help was provided one day in Autumn 1994 by a picture of a tree, with certain boxes for her to fill in with the appropriate names. Boxes were provided for brothers and sisters, so Katherine drew pictures of her half-brother, Alexander, and her two sisters Sarah and Christine. The box called ‘Me!’ she filled with her own named self-portrait. Daddy and Mummy both received their portraits as did Gran and Grandad on the paternal side and Great Gran, also on the paternal side. All were known to Katherine because all were alive. But Gran and Grandad on the maternal side were not known to Katherine because they were dead. The boxes were blank. There were already missing persons within Katherine’s view of her family. She had never known her maternal grandparents and therefore they somehow did not exist until they were pointed out to her and her sisters from the family photograph album. This does not necessarily imply a lack of family - many children are raised in families where they could not complete such a family tree. However, in some instances children could suffer as a consequence of such missing persons and missing helpers.

For a young carer, instead of only two of the six boxes being blank several more are blank. For various reasons, there are more missing persons than persons who are present, although the reason for their absence may not necessarily be death in the family. Instead of two ‘fit’ parents and three ‘fit’ siblings, there may instead be a physically impaired, ill or dependent relative. There is someone present who has to be helped in some way, and this can be particularly stressful to the child or young person. But there are missing persons and missing helpers: the people who need to be there to help the child or to perform the care directly are unavailable. The issues which arise from missing persons and missing helpers do not merely affect the lives of the numerous young carers who exist in our society. They affect all of us, because the majority of us live in families or family units of one sort or another. Even someone who lives alone will probably be part of a family. She or he has probably had a ‘family’, in the sense of living with her/him, in the past. If reasonably young, she or he may yet have a ‘family’ in this sense in the future. Young carers are part of our life because most of us have families. Young carers are also part of our life because we should all care about them and the responsibilities they face.

Changing Family Structures and Families in Crisis

What exactly is the family in the late 1990s, and where will it be by the 21st century? It is clear that social trends in relation to marriage and divorce have already changed

Notes and References

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1 Gillian Parker, Where Mist for Research on Carers? Nuffield Community Care Studies Unit, Leicester University, 1994.

2 Aldridge and Becker use this term to explain how some children are 'elected' or negotiated into the caring role by other members of their families. The children concerned do not choose the role for themselves. Jo Aldridge and Saul Becker (1993): Children Who Care: Inside the World of Young Carers, Loughborough University: Young Carers Research Group.
the structure of the family in late 20th-century Britain, and these trends are so widespread that they may be irreversible. Recent fiscal policy has tended to create a marriage trap disadvantageous for couples against a background of severe economic recession and consistently higher levels of unemployment than in any previous generation. At the same time, there has been considerable change in attitudes to marriage and sex before marriage - quite apart from a degree of sexual liberation for gay men and women - and heated debate about the role of men and women in the workplace and at home. For whatever combination of reasons, including legislative change, Britain has one of the highest divorce rates in Europe: the inevitable consequence is that many women, and some men, are lone parents exercising day to day care and control of their children. All sections of society are affected, including ethnic minorities. It is estimated that nearly one in five children will spend some part of their childhood in a lone parent family. Often the definition of family is that structure which has survived the collapse of a prior relationship between a couple. Not all lone parents may have experienced such a collapse however, for example, where a child is born as a result of a transient affair, as a result of rape or as a result of artificial insemination of a single woman or lesbian couple.

In a recent research paper on lone mothers and economic activity, Rosalind Edwards and Simon Duncan comment:

In Britain, in the past ten years, lone parent families have more than doubled in proportion, to reach 21 per cent of all families in 1992 - with over 90 per cent of them headed by mothers. In contrast to most other west European countries, British lone mothers are increasingly characterised by poverty and dependence on state benefits. Over 60 per cent now have incomes below half the national average, and almost 80 per cent rely on state benefits for the bulk of their income - double the proportions in the early to mid 1970s. Benefit levels mean that those who wholly or partially rely on them tend to exist on very low incomes.

Edwards and Duncan conclude that if poverty is 'part and parcel of lone motherhood', 'then this is a particularly British phenomenon', since the experience of other European countries shows that

reforms to the child care and benefit system - allowing lone mothers to take up paid work - can quickly remove the worst aspects of this association.

The absence of a full-time breadwinner for the family is a serious economic issue for lone-parent families. A survey of lone parents by Jane Millar and Jonathan Bradshaw in 1991 concluded that

Despite low pay, the women in employment had the highest overall incomes and it may be that employment offers the greatest opportunities for financial security and independence... [However] both the lack of available child-care and costs were major constraints upon working.

A follow-up survey of the same group by the two researchers in 1994 showed that

Lone parenthood is not a fixed or static status. A third of the sample had had some sort of change in marital status [between 1991 and 1994], a fifth moved into or out of employment and a similar proportion moved on or off income support. These changes in employment and benefit receipt were especially marked among the women who also changed marital status...

It is against this background that the costs of caring have to be considered. Although lone parenthood, in many cases, is not necessarily of long duration, lone-parent families are inherently vulnerable to crisis in the eventuality of a serious illness affecting the parent exercising day to day care and control of the children. Children are raised successfully by one parent, but, where two parents are involved, not only can some general family responsibilities be shared, but also a degree of informal health care cover may be provided to the family by the presence of the other partner.

Even so, many so-called 'traditional' families in terms of their structure (husband, wife, partner, children) experience long periods of stress or even crisis when they function virtually as lone-parent families - for example, where one partner is in prison or in an occupation which takes him (or her) away from the family for prolonged periods.

If illness strikes the partner who remains at home the stress may become a crisis. In the case of a family where one partner is in prison, there may be no alternative but for it to cope within its own resources; but where a partner works very long hours away from home, often commuting great distances, his or her continued employment prospects depend on acceptable cover being found for children and care for the ill partner at home.

Such stresses can in themselves serve as a cause of family breakdown.
Why Children Become Carers

The changing structure of many families, outlined above, can lead to children in lone-parent families becoming carers due to the absence of another adult in the household. However, many other young people may find themselves forced into a caring role not because they are alone in the world and there is no alternative carer, but because the (adult) person who has the primary responsibility to offer care refuses to accept the obligation to do so. In Aldridge and Becker’s study, for example, one young girl was required to look after her mother with multiple sclerosis because the father considered that ‘he had lost a wife’ and ‘wouldn’t dream of taking her out in the wheelchair’. Family stereotypes may reinforce the requirement that one family member, rather than another (perhaps more appropriate) person should perform the caring functions. All families have myths about themselves. Sometimes the myth will relate to the way in which the family functions (the argument, for example, that ‘we never have arguments or anything like that in our family’) or it may be prescriptive of expected behaviour (the comment such as ‘I’m thankful to say that none of the older relatives in our family ever had to go into a home’). The family’s anxiety over separation, rejection and death may be concealed by such myths. In a not too dissimilar way, one young member of a family may be presumed to have a propensity for caring which others lack and therefore have an inherent duty or right to assume this role.

Why should a child have to assume a caring responsibility which the father ‘finds it hard to face’? It may be that the family had been functioning for some time as if it were a lone-parent family. Although it is important to recognise the small number of lone fathers bringing up children, the general position is that many men are unable or unwilling to accept an active role in parenthood. Some men may be unwilling to accept an active caring role should this become necessary because of the sudden, unexpected, illness of a partner. Occasionally, in the situation of a lone father the reverse may be true - the mother has not been prepared to assume a full parental role, and is equally unwilling to take on a caring role with regard to an estranged partner. The onset of a serious illness may in any case bring about a permanent rift between partners in a relationship, leaving the young person as the sole carer. Siblings may be quite unwilling to accept a share in a caring role, which therefore falls on a single family member either because of gender assumptions (that caring is girls’ or women’s work) or because of an inhibition arising from the sex of the person to be cared for. For example, in Aldridge and Becker’s study, one young female carer, caring for her mother, commented about her brother, ‘Paul can’t do much because it’s a woman’. There may nevertheless be persistent criticism from inactive older family members about the young person’s caring abilities. Family members may become alienated when one young person is forced to assume a caring role rejected by a brother or sister: another young carer in Aldridge and Becker’s study commented of a sibling: ‘...he just didn’t want to know. I can’t forgive him for that.’

There is a complex motivation for young carers who to some extent are directed into their role by a parent, but often seem to accept the role which they may not have chosen positively (this half-way house between choice and drift is what Aldridge and Becker term ‘election’). Young people are elected into this role, it may be suggested, rather than choosing it positively, and they do so ‘through lifestyle, through emergency, through habit, compassion and... through love’. One of the parents interviewed by Aldridge and Becker commended that children ‘are the best people to provide the care because of love’. Another said: ‘I think it’s not really sympathy, I think it’s more out of love.’ Whatever the precise combination of reasons which leads young people to become carers, they invariably assume this role either because the parent or other family member rejects support from outside, or because that support is insufficient, or missing.

The Consequences of Caring

The responsibilities placed on young carers are a matter of concern to all of us for many different reasons; but of primary importance is the potential long-term psychological and psycho-social damage which may occur as a result of being required to assume too much responsibility suddenly and too early in their lives. The suddenness of the change caused by the serious illness of a family member is a problem because it removes the natural pattern of a child’s development, whereby responsibilities are assumed gradually and (preferably under parental guidance) in an orderly way. Thus, a child who wears lace-up shoes is not expected to dress herself or himself entirely until the shoes can be tied up; a child is not expected to assume responsibility over some part of the money affairs of the family until he or she can count, and so on.

Clearly, children mature at different rates; some mature earlier than their peers. But it is rarely the case that a child matures in all aspects of her or his personality simultaneously: an early advance in reading and

9 Miriam quoted in Aldridge and Becker, Children who Care, op. cit., p. 32; Jo Aldridge and Saul Becker, Punishing Children for Caring: The Hidden Cost of Young Carers, Children and Society, 7 (4) (1993), 376-87, at p. 380.


11 Miriam quoted in Aldridge and Becker, Children who Care, op. cit., p. 32.

12 See, for example, the case of Jimmy detailed ibid., pp. 13, 55.

13 Miriam quoted ibid., p. 33.

14 Jimmy quoted ibid., p. 33.

15 A term coined by Aldridge and Becker in Children who Care, ibid.

16 Maureen Ossim, response in Parker, Where Next for Research on Carers?, op. cit., p. 17. Maureen used the expression ‘drift into caring’, however, which we have avoided for the reasons given.

17 Mrs Winterbottom and Mrs Mirza, both quoted in Jo Aldridge and Saul Becker, My Child, My Carer: The Parents’ Perspective, Loughborough University: Young Carers Research Group, 1994, p. 19.

18 ibid., p. 32: ‘So, despite parents acknowledging the unacceptable nature of certain child carers’ tasks, the parents relied on the child to perform them - and they also said that they would not wish for anyone else to perform them.’


20 Aldridge and Becker, Children who Care and My Child, My Carer, op. cit.
literacy skills at the age of say, six, may be combined with a relative slowness in some of the physical skills; and this asymmetrical development may continue throughout the child's early years, though the gap between the range of skills may narrow. To expect a young person to assume many or all of the responsibilities of a household simultaneously in one sudden transformation is to expect far too much. An intense sense of the loss of childhood is one possible consequence.\textsuperscript{11} Another is the sense of being punished for caring: 'The unexpected change in her family circumstances, the sudden onset of caring responsibilities, coupled with the grief over the loss of her father can so traumatised a young person that the new caring role can appear as a punishment for something she had unwittingly done wrong.\textsuperscript{12}

This sense of punishment may be reinforced by the embarrassing, or even repugnant, nature of some of the tasks performed by young carers (cleaning up after dad 'lost control of himself'; bathing a naked parent; emptying of catheters, and so on).\textsuperscript{20} And it is almost invariably the case that the child's educational development is hindered by the assumption of a caring role, which tends to lead to absenteeism and an inability to cope: 'how am I supposed to get on well in school?', one young carer asked.\textsuperscript{21}

Since a sense of isolation is one of the features of being a young carer,\textsuperscript{16} many of those who find themselves in this position do not recognise that there are others in comparable situations. They lack objectivity about themselves and their problems precisely because the caring role is here and now, and the need for help is immediate. Only when there is a sufficiently large group of young carers who have been interviewed at various stages in their caring role, and whose responsibilities have come to an end, will the full range of possible outcomes be known.

Yet several patterns are reasonably clear from simple observation and conversations with individuals who do not necessarily recognise that they exercise, or have sought to avoid, a caring role. One underlying pattern which is true of many families, and which would be revealed by the careful construction of the family tree or genogram, is that successive generations within a family elect an individual or individuals for a caring role, and that this process of election may occur at an early stage in the child's development.\textsuperscript{22} In one family known to us, the father saw certain personality traits as dominant in one daughter (Jenny) which were absent in the other (Sarah). The father is dynamic at his job, works very long hours away from home and views success in terms of being in control of a business enterprise and making a great deal of money. Jenny is successful at school, leaves for university, makes a success early on in her career, marries and has children. The mother is in many ways the opposite personality to the father and is withdrawn. She does not expect support from Jenny, because the father's world view of the slightly older daughter prevails, and is successively confirmed by events. Sarah is regarded, and has always been regarded, as much more like her mother than her father. From an early date, the mother was in effect a lone parent bringing up her children and a close relationship of mutual dependence developed between Sarah and herself. Sarah left for university, but encountered difficulties in her studies and in finding employment. She now lives with her mother, while the father works abroad. The parental model of the two children has been confirmed by events and seems to have become a stable set of relationships in which one child lives at home to provide the mother with support; both mother and daughter accept this interdependence. Strictly speaking this is not defined as a caring role; there is neither personal care exercised for a sick person, nor are there general responsibilities which have to be exercised by the young person because the mother is unable to undertake them herself. Yet neither is a complete person without the other and this mutual dependence is similar to that experienced in many caring relationships.

In other cases, the child may break free from the family tie and reject the role which is presumed for her by one or both of the parents. Jenny did so. In another family known to us, Elaine may do so once she leaves home at the age of sixteen or seventeen. While she remains at home, there is great tension because of her refusal to accept a caring role which both parents assume to be hers, with regard to her young stepbrother. Elaine bitterly resents the imposition of a caring role by parents who are themselves estranged and feels that she is being made to pick up the pieces left from the breakdown of her parents' marriage and the illness of the mother. But even when Elaine leaves home, it is not inevitable that she will break free from the responsibility of care.

Another example with which we are familiar is the case of Jeremy who comes from a quite different set of family circumstances. His mother misuses alcohol, and there are frequent appeals for help. To continue training for his career, he must complete his studies; but this is impossible if he continues his caring role with regard to his mother. Moreover, he finds great difficulty in
organising his time, controlling his personal life, and preventing himself from falling into debt. Deep down, he may fear that he, too, will have an alcohol problem. Can Jeremy preserve his own identity, and train for his career, while continuing any sort of caring role for his mother?

Sarah, Elaine and Jeremy are all in their teens and it is impossible to predict how their lives will be resolved. They may be scarred by a caring and supporting role which they did not choose for themselves; they may have derived some positive benefits from experiencing such a role; or they may experience both positive and negative aspects. If a personal relationship is formed which leads to cohabitation or marriage, and subsequently to children, will some of their experiences be projected on to the next generation?

There is some anecdotal evidence that unstable relationships can result among some young carers. Let us take an example with which we are familiar. Tracy is now in her early forties. At the age of ten or so, her mother died. She had other brothers and sisters, but her father expected her to assume the full caring role in the family, which had previously been exercised by her mother, while he continued in full-time employment. Tracy did not understand the rudimentary principles of balanced diet for the family. The children were fed on a diet high in sugar content with the result that their teeth deteriorated. Some of the children also developed a weight problem. Control and discipline were resolved largely by the older children being given responsibility for their younger siblings, whether or not they could exercise it effectively. Reading and learning difficulties were experienced by the younger members of the family. Now Tracy has her own family of six children, with a wide age range between the oldest and the youngest. Her husband works long hours for relatively low pay, with the result that the family lives on the margins between self-sufficiency and unmet need. Tracy has the sole responsibility for managing the family’s finances, but because of her own poor education lacks any ability to budget. From time to time, the family finds itself in debt.

Two or three years ago, she saw the way forward clearly: she would work as a childminder, away from home, while her eldest daughter, Linda, would remain in the family home and be responsible for her youngest son, Jimmy, then aged two and going through a difficult stage of development. This employment would benefit the family income, and Linda would earn her board and lodging by looking after Jimmy. For a while, this plan worked, but in the end it came to nothing, and Tracy had to give up her paid employment. Linda had become resentful of the isolation she experienced in remaining at home to look after Jimmy. She married prematurely without her mother’s consent in order to leave home and become financially independent. Her mother refused to go to the wedding, not least because the husband was not a member of their religious group. Tracy had found over the years that some of the deep insecurities resulting from her personal history were assuaged by membership of a church which told her how to lead her life. She could not altogether live up to the requirements of membership, one of which was the avoidance of debt, but nevertheless to be a part of this community provided Tracy with something that was more secure than anything else she had ever experienced. Yet despite the existence of this strong community link, the family’s problems still occurred in isolation. Tracy had effectively been let down by her faith community, which represented a ‘missing helper’. It was because of the isolation she felt that the pressure on Linda had developed to a crisis point. Linda’s break was not merely with her mother and a caring role she did not wish to assume, but also with the imposition of a set of values which constrained her own lifestyle. The daughter was able to abdicate a responsibility which the mother had been forced to accept at a younger age by a more dominant father.

Supporting Young Carers and Their Families

There is a particular need for information for all carers, particularly those dealing with people whose personality may undergo periodic change, including violence. Maureen Oswin states that when she cared for her mother, who had Alzheimer’s disease, she received no advice at all. If adult carers find it difficult to access information and support, then one can assume that children may be in an even worse position. Fear and stigmatisation may contribute to the reluctance of families seeking support and information. Some types of illness may be particularly stigmatising, for example mental health problems, drug or alcohol misuse, AIDS and HIV.

All families affected by HIV - where a member of the family is HIV-positive or has AIDS - require support because of the sense of isolation and alienation, social stigma or ostracism, which may result. Yet for many families it can often be psychologically difficult to seek help and advice; moreover, whereas in London there are many support services, outside the capital it can be more difficult to know whom to

27 At the launch of the report by Sandra Bilkisborrow, “You Grow Up Fast as Well...” Young Carers on Merseyside: Liverpool Bernard’s, Personal Services Society and Carers National Association, 1992, young carers reported from the platform that they had had difficulties in forming and maintaining relationships and that they had all sought professional therapeutic help. In many other conferences around Britain young carers report similar problems.

28 Young carers in Aldridge and Becker’s studies report their shock at having to deal with parents whose illness led to severe personality change and to violent incidents within the home. Aldridge and Becker, Children who Care: op. cit., Aldridge and Becker, My Child, My Carer: op. cit.

approach for help and support. Alerting the children of such families as to the likely medical prognosis requires careful handling. The need is to promote the rights of children infected or affected by HIV, to increase knowledge and understanding about the impact of HIV on children and families, to combat prejudice and discrimination, and to encourage the development of services, policies and practice which are child-centred and enhance the quality of life for children and families. It is crucial to break down the barriers of distrust and alienation if families stigmatised by HIV infection are to receive appropriate help and support: ‘Families have to be convinced that services are open, non-judgmental and accessible...’, argues Naomi Honigsbaum in a study on AIDS and children; ‘Family counselling for all members may be essential...’

The presence and support of a partner may be crucial in the different types of deteriorating case outlined above. Such presence and support is likely to become even more important with the suggested reduction of the state’s commitment towards the financial and care needs of older people within an increasingly ageing population, changes which have been termed the ‘individualisation of the responsibility for care’, or ‘“self-reliance” for care provision’. In the absence of a partner, the role of carer may fall to children within the family.

It is important to recognise that family relationships, marriages and partnerships may be threatened by support services coming in from outside. Balanced against this risk, however, is the fact that deep-seated family pride carries a heavy cost in terms of isolation and stress when a family finds that it has to cope with the consequences of disability or a progressively deteriorating condition. Disability does not necessarily affect an adult’s capacity as a parent per se (disabled parents can usually continue to care for a child’s emotional welfare and to parent their child in many other ways), but it invariably affects parental activity: that is, the disability prevents parents from doing things that other, non-disabled parents would do. On the other hand, severe multiple disabilities, terminal illnesses and deteriorating conditions are likely to lead to extreme incapacitation which may preclude not only ‘normal’ parental activity but also effective parenting. As Maureen Oswin, a former carer, has commented: ‘People who require care are not always articulate disabled people. Thus, sick or disabled parents may not request services because of lack of information, fear or stigmatisation and may, through lack of effective services, find their ability to parent their children undermined.

In general, the prevention of family breakdown and the preservation of long-term stable, secure and committed relationships should be the key aspects of any policy towards family life. There needs to be better and more support for couples, both married and unmarried, especially with regard to relationship guidance and parenting. ‘Parenting’, it has recently been argued is still too often seen as mothering, and indeed is still largely done by mothers... The need to see parenting as a shared responsibility, and to involve boys and men in preparation, education and support for parents is crucial, both for the health of families, and in order to raise the low status of parenting in Britain.

Such support needs to come from a range of intermediary organisations such as schools, churches, other religious bodies and faith communities, and specialist voluntary bodies such as Family Service Units (FSU) and Home-Start.

Since families in need are not always aware of what specialist help is available to them, it is worth outlining some of the activities of FSU and Home-Start, though other organisations will also be relevant. For nearly fifty years, FSU has supported families and children in coping with the threat or result of family breakdown; helping develop parents’ skills and resources in caring for their children; encouraging families’ self-confidence and self-esteem; meeting the diverse needs of minority ethnic communities and responding sensitively and creatively to local community needs. FSU claims to be a flexible service designed to meet each family’s individual needs. Locally-based FSU teams, staffed by trained workers, backed by volunteers, offer:

- intensive counselling for children, adults and families;
- help for families where children are at risk of physical or sexual abuse, or neglect;
- therapeutic and specialised groups for children, young people, and parents facing common problems;
- practical help in the home;
- advice on welfare rights, immigration, housing and finance;
- support for parents and carers;
- play schemes, holiday, after school and educational projects;
- ‘drop-ins’, community-based activities;
nurseries, play groups and other special services for the under 8s.\textsuperscript{3}

A second specialist organisation, Home-Start, has recently celebrated its 21st anniversary. Families with at least one child under the age of five stand to gain because Home-Start schemes:

- share with families advice and information gleaned from a wide variety of agencies;
- gain invaluable support from health visitors, social workers and other professionals who help them to help families;
- benefit from other organisations, for example through free use of premises, an office or somewhere for families to meet and for children to play;
- foster links with agencies and organisations which support varied activities.

Partnership underpins Home-Start schemes making it possible for families to have:

- someone with time for them who will visit regularly, listen and where possible try to meet their needs;
- a friend who supports the family if required but does not take over decision-making;
- someone who will help parents with their children.\textsuperscript{3}

We have highlighted FSU and Home-Start as examples of voluntary organisations dedicated to supporting families in difficulty, in order to prevent permanent breakdown. There are other examples, such as the family centres and neighbourhood projects of The Children’s Society,\textsuperscript{4} and so on. The existence of such organisations suggests that it is possible for a family in crisis to find support and help, although much depends on what is available locally.

In some cases the early recognition of the need for such support and help would prevent one of the long-term reasons for the phenomenon of young carers, namely that in many such families there is only one partner left in the family structure and only children remain to support that parent once he or she becomes seriously ill or disabled. Even so, two of the most obvious difficulties faced by support organisations are families’ lack of awareness of what help is available; and families’ suspicion and resistance to receiving help from outside. These difficulties are fundamental and confront all forms of support to families, including support to carers in families. Often the help is not sought until very late (one hesitates to say that it is ever too late for help), and this delay may arise both from lack of awareness and the wish to remain independent. The family may nevertheless experience difficulties due to a lack of provision of services in some areas, or restricted funding of agencies which means that they can cope with only a limited number of cases. It is invariably the case that the statutory agencies find it very difficult to respond quickly to requests. The general principle must be that earlier assistance is sought, the more chance there is that the family’s requests and needs can be met. Decisions made in an atmosphere of crisis are rarely good decisions.

Here, the effectiveness and support of the General Practitioner (GP) is a real issue.\textsuperscript{30} Dr Leon Polnay, a Consultant Community Paediatrician and Reader in Child Health, argues that

It would be a desirable development that every health record includes an up to date family tree, that individuals with disabilities are identified and the question asked, ‘Who is the carer?’ The combination of family tree and services tree will provide a basis for ensuring that young carers and their needs are not overlooked.\textsuperscript{41}

Local social services and health authority Community Care and Children’s Plans/Charters will provide a valuable policy and organisational context in which key decisions about family life may be taken. The challenge is for the statements to be put into operation. Provision should be flexible, recognising that people have a range of needs to be met; provision from health, social services and education might be purchased through collaboration and joint planning arrangements where the voluntary sector could take an active lead. In certain localities, the voluntary sector may be able to take the initiative; in others, multi-disciplinary teams, including health and social services, can look at the whole family’s needs and help to bring about a sense of trust and stability in the provision of care. However, in many localities such multi-disciplinary teams simply do not exist, and care provision is fragmented. For the young carer, the Education Welfare Officer may play a more important role than the GP, but such professionals need to have full knowledge of the relevant issues and to be sympathetic to the needs of families experiencing this sort of caring crisis.

Teachers also need to be aware of the possibility that the truant, the troublemaker, or just simply the tired pupil, out of school hours (and indeed in them), may be a young carer.

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\textsuperscript{37} FSU leaflet (1994), FSU National Office, 207 Old Marylebone Road, London NW1 5QP. Phone 0171 402 5175.

\textsuperscript{38} Sheila M. Shinnan, Sue Pope and Sue Everitt, Family Album. Snapshots of Home-Start in Words and Pictures, Leicester: Home-Start UK 1994, p. 105. Home-Start UK, 2 Salisbury Road, Leicester, LE1 7GR. Phone 0116 255 4998.

\textsuperscript{39} The Children’s Society, Edward Rudolf House, Margery Street, London WC1X 9JJ. Phone 0171 937 4259.

\textsuperscript{40} Parker, Where Next for Research on Carers?, op. cit., p. 15: ‘The GP has always been an important potential source of advice and a gatekeeper to other services for carers, although the degree to which support is given seems to depend on individual GP orientation to their work rather than any widespread recognition of carers’ needs within the profession.’

\textsuperscript{41} Quoted in: Chris Dearden, Saul Becker and Jo Aldridge, Partners in Caring: A Briefing for Professionals about Young Carers, Young Carers Research Group, Carers National Association and Crossroads UK, 1994, p. 3.
For their part, families need to become aware of the national and local carers' support and young carers' support groups. In some areas, networks of carers' workers exist and publish useful contact lists. From such lists it is possible, for example, to find the name of the local carers' Support Officer from the Alzheimer's Disease Society, whose work responsibility is to support carers of people with that disease and other dementias; support for carers of those with learning disabilities may be assisted by Mencap, while the MS Society organises respite care for people with multiple sclerosis, an illness which requires the support of a significant number of young carers. In some areas, there are important initiatives whose purpose is to care specifically for young carers. Thus Barnardos fund a project in Leeds, The Willow Project, which helps 'young people caring for a relative with a mental illness to continue with their school lives and other interests which often suffer when teenagers become carers'. Support offered includes 'counselling, social, leisure and educational activities such as outings and special trips'.

Crossroads schemes deliver respite care to over 22,000 people in their own homes annually, thus providing vital relief for primary carers throughout the UK. Crossroads also has a number of projects helping young carers, including one in St Helens (where 160 young carers are given therapeutic and counselling assistance); another in Nottingham, which offers general support and respite care; and one in Halton, Cheshire, which is concerned with the educational needs and experiences of young carers. The King's Fund Carers Unit provides publications and helps develop local support for carers.

Statutory and voluntary agencies must work together to provide an integrated range of services, carefully geared to the requirements of each family member. They must now begin to:

- include provision for young carers when planning future services, and look at innovative approaches such as advocacy and befriending;
- revise training programmes to ensure a sensitive and consistent response from staff;
- make home care support services more accessible and appropriate to children;
- address the additional stigma which can face children of those with mental illness, AIDS, genetic disorders, or difficulties with substance abuse;
- examine their approach to ethnic minority families, where children often act as interpreters as well as young carers.

In addition, there are now more local Young Carers' Action Groups and, since 1992, the Young Carers Research Group at Loughborough University has developed a range of information and training materials for professionals and young carers as well as interviewing young carers and parents about their needs and aspirations.

Community Care and Young Carers

In a family where a young person has to assume an undue caring role:

Community care... is effectively care by children, and children bear the costs of this role in terms of their childhood, development and security.

Caring, moreover, is and should be seen as a paid work: 'caring is their work, and yet there is no economic recompense of recognition for such employment'. There is, moreover, some evidence that instead of young carers receiving assistance, in some cases professional support - for example, community care assistance - is withdrawn as an acknowledgement of children's abilities as carers. But there is inconsistency in the definition of the 'suitable' age at which young persons can provide care themselves, which may vary from 12 to 16. Yet it may be the case that only a small amount of appropriate support is required at the right time to avoid a crisis in the life of the young carer. The more forward-looking authorities now recognise the importance of a flexible and relevant degree of support to carers and young carers in particular. We may take Leicestershire's Community Care Plan.
1994-95 as an example of good intentions. Among other steps, it proposes to:

- work with Home Care Managers and Day Centre Managers to identify ways of obtaining feedback from carers so that services can become more flexible and responsive to individual needs. Consultation with carers will measure the effectiveness of this work.
- develop and deliver training packages for key statutory and voluntary sector staff to raise the profile and awareness of carers' issues;
- encourage and enable carers to help with training of staff who undertake assessments;
- work with the voluntary sector to develop carers' support groups, befriending schemes, setting services, care attendant services, as appropriate, in areas of the County which currently have no such provision;
- in relation to the proposal for development of a Carers' Home Support Service pilot scheme in the City, evaluate the need for this proposal in the context of the wider development of relevant services for carers in the City and County;
- work with the voluntary sector to submit a bid for funding to develop at least one Crossroads Scheme in the County to offer a flexible respite service for carers;
- prioritise researching and addressing the needs of child carers. Work with the network of carers' workers to undertake research into the development of an information pack for child carers and organise a multi-disciplinary conference to address child carer issues and raise the profile of child carers and their needs;
- research and begin to develop a database to enable the Carers' Support Unit to act as a central broker for carer-related information in the future;
- attend at least 10 meetings of carers' groups and forums to ensure ongoing consultation with carers and deliver informal training packages to inform and to enable carers;
- prioritise consultation with carers of people with mental health related difficulties and carers from minority ethnic communities. Design and disseminate a 'signpost' leaflet for carers in order to direct them to appropriate services and sources of information. Leaflets to be piloted with carers prior to production and reviewed and updated every 12 months.

- make a start in promoting, employing and training of carers' advocacy workers within the Voluntary Sector to support carers in planning situations and to assist individual carers in expressing their views and/or pursuing complaints.

Many of these good intentions still have to be put into practice. Training and Briefing packs such as Getting it Right for Young Carers: A Training Pack for Professionals (prepared by the Young Carers Research Group, Loughborough University on behalf of Crossroads) and other materials for professionals who are likely to deal with young carers are of great importance in disseminating ideas. Many young carers continue to regard social workers with suspicion or even hostility. There are several reasons for this. Bad relationships, or relationships which lack any relevance or meaning, may be one cause. But an underlying reason is that the social worker is perceived to be an authority figure, who may threaten 'care proceedings' early on in the relationship, which is therefore blighted by the fear that the young person may be separated from his or her family. This fear tends to reinforce the sense that young carers are being punished. They are being punished by having to assume a caring role for which they are not ready and for which they may be unwilling. This can also become a double punishment in their mind if they are then taken into care for an apparent inability to cope with caring responsibilities.

To be punished for caring is hard to comprehend when you are a child carer. And the messages that this gives children during a critical stage of their psycho-social development may influence the way they perceive, and value, caring and family responsibility in adult life.

The Role of the Church and Faith Communities

Much of the discussion of the problems faced by families, carers and young carers in particular takes place purely in a secular context. The possibility of a supportive role from the faith community into which the family was born, whether or not the faith is openly professed by any of the family members is rarely considered. Yet clearly the relevant faith community may have a special role to play for non-Christian families, while for Christians there exists the Carers Christian Fellowship. There is a spiritual dimension to such work, whether or not the young carers and their families are aware of it. The term 'spirituality' is not one which most people are aware of or

52 Aldridge and Becker, 'Punishing Children for Caring', op. cit., p. 384.
53 ibid
54 Saul Becker, 'Children who Care: Inside the World of Young Carers', unpublished paper delivered to the British Association Festival of Science, Loughborough University, of Technology (8 September 1994), pp. 7-8; Aldridge and Becker, Children who Care, op. cit.
55 Leicestershire's Community Care Plan, 1994-95, p.51, s.v. 'The needs of carers'.
56 See note 47.
57 Young Carers' Information Pack for Leicestershire, prepared by Young Carers' Action Group organised by Leicestershire Network of Carers' Workers (Leicestershire Association of Voluntary Agencies, Beaumont Enterprise Centre, Boston Road, Leicester LE4 1HB. Phone 0116 234 1371)
58 Dearden, Aldridge, Newton and Becker, Getting it Right for Young Carers op. cit.; Dearden, Becker and Aldridge, Partners in Caring: A Briefing for Professionals about Young Carers op. cit.; short briefing paper by Leicestershire Young Carers' Action Group.
59 Jimmy quoted in Aldridge and Becker, Children who Care, op. cit., pp. 41-2.
60 Aldridge and Becker, 'Punishing Children for Caring', op. cit., p. 381.
61 Aldridge and Becker, 'Children as Carers', op. cit., p. 460.
62 Carers Christian Fellowship: Mrs. Brenda Baillie (Secretary) and Mr. Chris Baillie (Administrator), 14 Yealand Drive, Ulverston, Cumbria LA12 5JB. Phone 01229 586574.

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even understand. It is also notoriously difficult to define.\(^3\) One sense of the term 'spirituality' describes the motivation, or sense of commitment, people bring to the task of helping or providing for others. Care for one's family, and one's neighbour, has been a central aspect of the Judeo-Christian tradition. The fifth commandment of the Ten Commandments or Decalogue was to 'honor your father and mother' (Exodus 20:12; Deuteronomy 5:16). As the recent report of the Church of England Working Party on the Family (1995) puts it:

The social vision implied is one in which personal identity is bound up with being a member of a household whose allegiances cross the generations, and in which the interests of individuals are served best by their contribution to the extended family group...[T]his has relevance for modern societies where people are living longer and elderly people make up an increasing percentage of the population.\(^4\)

If the family was central to the vision of the Hebrew Bible, the teaching of Jesus stressed that the first or great commandment was that the love for God and for one's neighbour cannot be separated (Mark 12:29-31; Matthew 22:37-40; Luke 10:25-28). This in turn linked together two separate commandments from the Hebrew Bible (Deuteronomy 6:5; Leviticus 19:18) as a single precept: 'Love each other as I have loved you' was Christ's command (John 15:12). True spirituality, in the teaching of St Paul, is genuine love for others: 'If I have no love, I am nothing' (1 Corinthians 13:2). Spirituality, within this definition, is akin to love for others. You do not have to be 'religious' to care for others, but the most effective forms of caring take place within a loving, persistent relationship.\(^5\) Continuity in the caring relationship is what matters, but such continuity has to be sustained. It is therefore not inappropriate to talk of a spiritual dimension to the work of young carers, most of whom give generously of their time, and at considerable personal cost to themselves. This spirituality needs to be nurtured and strengthened by whatever support networks exist, whether religious or secular. The Church, or faith community, needs to be (in the words of the report of the Church of England Working Party on the Family) a 'family of affiliation', encouraging the formation of such other family-type groupings to support the many people 'who feel themselves otherwise to be outside the family' and to enable them to 'become full insiders again'.\(^6\)

Research has suggested that young carers and their families may prefer voluntary sector help - which could include members of the Church or faith community - to be involved in providing support rather than professionals from the statutory sector.\(^7\) The specific role of the Church and faith communities has been identified as assisting the spiritual support of carers; befriending carers; relieving the carer; supporting other agencies caring for carers; giving practical help for carers, including helping prepare meals, offering transport, helping with gardening and housework; and helping former carers.\(^8\) Two of these forms of assistance have not been mentioned before, but are particularly relevant in the Church and faith community context:

- **Assisting the spiritual support for carers.** There is a need for the Church and faith community to offer spiritual support in a non-coercive way, where such support is requested. It is also the case that young carers are often unable to attend Church or other places of worship. If offered short-term respite care, some may take the opportunity to go to places of worship or Church/faith community-based youth group meetings.

- **Befriending carers.** The Young Carers Research Group has published a detailed report on the guidelines and principles for befriending young carers.\(^9\) Members of faith communities may have a valuable contribution to make as befrienders. Volunteer training would need to take the form of pre-placement (and post-placement) training sessions; guidance would be provided on the needs of young carers, the befriender's role, including boundaries in the befriender-younger carer relationship, support networks, and the relationship with the young carer's parent or carer receiver and other family members; children's rights and children at risk issues and child protection procedures are also important.

In the context of the Church, the help offered by individual churches can be greatly enhanced when churches work together, preferably ecumenically, as has been found in the experience of the 'Watford Carelink: Churches' Concern for Carers'. What most carers wanted was:

A regular, trustworthy visitor who could take on their caring task for a short amount of time on a regular basis and at a time most beneficial to them... Volunteers would give a few hours of their time, weekly, fortnightly or even monthly to sit with the elderly person whilst the carer relaxed from (his or her) caring tasks. The carer could go to meetings, go shopping, do the gardening, or even go to sleep for a few hours. The choice would be
Theirs - but this small break can make a big difference.8

A Children’s Society briefing note quotes a parishioner on what such a supportive role can mean for the helper:

Often, church members are exhorted in general terms to become involved in the community but are at a loss to know how to do this in practical terms. Being involved in this project [reaching out to local families under pressure] has given me a way to do this, increasing my confidence and opening up the possibilities of linking my faith with a social concern.71.

The Carers Christian Fellowship Newsletter comments:

Where the church family is kind and supportive, a carer’s load can be considerably lightened. However, when fellow Christians appear insensitive and unconcerned, carers feel hurt and can even be led to question the love of God. Members of the Fellowship are divided between those who express gratitude towards their churches for the help they have been given and others (sadly in the majority) who feel let down and forgotten.72

Clearly, much still needs to be done.

Conclusion: Towards a Partnership Between Faith Communities and Others

Two recommendations of the recent report of the Church of England Working Party on the Family provide useful background to our conclusions. One concerns the pastoral care of members of the Church or faith community:

We recommend that when it offers pastoral care to families, the Church move its focus from the individual to the family group as a whole, in order to understand and respond to the interrelated needs of individuals within their family relationships.79

The second recommendation addresses the need to support carers:

Caring for a dependent relative can be very rewarding but the personal cost is often high. Caring may disrupt careers, detract from other relationships and lead people into poverty and social isolation. We recommend that carers be given adequate financial and emotional support and help not only from professionals, but from the wider community.84

The first of these two recommendations meets the point which we have raised in this discussion paper, that the interrelated needs of young carers and the person being cared for have to be addressed. The second recommendation, if implemented, would meet our central concern that young carers are personally disadvantaged by the exercise of their caring role. No single proposal or set of proposals can ‘solve’ the situations and circumstances that create the need for young carers, nor can they meet the competing needs of young carers and those for whom they care. But spreading the net as widely as possible, and getting to families in crisis as early as possible can make a significant difference.85

First of all, the ‘seeking help’ hurdle has to be overcome. It is much better if the family in need, or at least one of its members, takes the first step in seeking help. Other family members still have to accept that the family has a need which can be met by a helper who is also a friend. Sometimes, if the family cannot overcome the hurdle of seeking outside help, a friendship may be formed which in itself can provide a degree of help. It is the isolated family unit, without friends or any network of support, which really experiences crisis.

Carers do not always need to be drawn from within the family itself. Family Group Conferences, as advocated by the Family Rights Group86 are a way of involving voluntary sector workers, professionals and the family in collaborative decision-making, while leaving the family with the right to agree on its own plan. Successful plans require a co-ordinator who is trusted by the family, and if requested by, or acceptable to the family this person could well be a member of the Church or faith community. In many circumstances it would at least be appropriate for a member of the Church or faith community to form part of such a Family Group Conference, one of the aims of which would be to balance the competing interests of the person cared for and the young carer. Disadvantaged families and families experiencing crisis are precisely those groups which find it most difficult to gain access to services. Advocacy, that is assistance in mobilising the arguments by which resources and help may be secured, including mastering the technical details of the case, is a crucial form of help. Members of the Church or faith community can play their part by being well informed and becoming friends and advocates of families in need.

Once the ‘seeking help’ hurdle is overcome, and the family begins to receive support from outside, it is important to recognise that both the person being cared for and the

70 Carers Christian Fellowship Newsletter, 5 (May-August, 1984), p. 2. Volunteers in this scheme are asked to provide two references and all their expenses are paid.
71 Children’s Society sheet PRIB108 entitled ‘Working with the Church’ within the publicity pack ‘Making Lives Worth Living’ (The Children’s Society, Edward Rudolf House, Margaret Street, London WC1X 8JL. Phone 0171 837 4289).
73 Something to Celebrate, Valuing Families in Church and Society, op. cit., p. 211 (recommemation italicized in the report).
74 Ibid., p. 214 (recommendation italicized in the report).
76 Family Rights Group, Print House, 18 Ashwin Street, London E8 3DL. Phone 0171 823 2828. The model originated in New Zealand with the aim of offering a more relevant and respectful service to the Maori community but has since spread across the whole population. Adapting this model to the particular needs of young carers, stage one would include a meeting with the family interpreted as widely as possible that is, including relatives and non-related significant adults, who might include a member of the faith community. Stage 2: at the start of the meeting, the relevant professionals share their knowledge, views and any concerns with the family, and answer any questions the family may have. Stage 3: the professionals withdraw, leaving the family alone to plan its care needs. Stage 4: once the family has agreed a plan, the professionals rejoin the meeting and agree any necessary involvement or specific course of action with regard to outside support for the young carer.
carer or young carer have needs, rights and responsibilities. Successful support has to assist in the discharging of responsibilities and to meet at least some of these frequently competing - needs and rights. Both practical help and 'spiritual' support need to be offered on a regular basis, preferably by one person assigned to a family for the period of need. (There may be an intermittent but recurring caring role which has to be supported.) 'Spiritual' support is interpreted in a wide sense of the term. It could take the form of support from the relevant church or faith community. It could take the form of non-judgmental listening, both for the young carer and the person being cared for. There may be more general counselling needs or special needs, for example following bereavement. Despite all the obvious procedural difficulties, practical help could take the form of local volunteers recruited, trained and organised by an experienced organiser, similarly to the Home-Start model, who would provide help in the homes of those in need. Clearly resourcing is needed for the organiser, and there has to be a will to organise voluntary support for young carers; some of this voluntary support might be found among the Churches and the faith community.

It is simplistic to believe that young carers' needs can be completely eliminated; nor is it enough simply to support the efforts of existing young carers without doing something to address the fundamental reasons why this caring role arises in the first place. No one has a monopoly of wisdom, but a flexible range of solutions in a partnership between the family, existing statutory agencies, and different types of voluntarism - sometimes drawn from 'secular' voluntary agencies, on other occasions from the Church and faith community - may offer in the future the best hope for an improved lot for young carers and their families. Working in partnership will go some way towards replacing those persons and helpers missing from the lives of young carers, and in some cases may prevent such absence in the first place. A strategy which aims merely to re-educate older people not to expect the younger generation to care for them will be too little and too late. It will not assist the lot of many young carers, because not all the older generation will be 're-educated'. And it will not necessarily provide the care that is required for such older people when, for a combination of reasons, health and social care provision in the localities is found to be insufficient or unsatisfactory.

**Other Young Carers Research Group Publications**

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A discussion paper by Richard Bonney with Saul Becker

This discussion paper aims to bring to the attention of the faith community of whatever denomination the competing needs and pastoral issues which arise from the caring responsibilities placed on persons under the age of 18. It suggests ways in which support can be offered to families experiencing difficulties in care provision and seeks to heighten awareness of, and information about, the various issues involved with young carers and those for whom they care.

Professor Richard Bonney has been Professor of Modern History at the University of Leicester since 1984. He is an ordinand in training for non-stipendiary ministry in the Church of England and his wife, Dr Margaret Bonney, is Chairman of the Family Life Committee.

Dr Saul Becker is Director of the Young Carers Research Group and Director of Studies for the interdisciplinary Masters Degree programme in Policy, Organisation and Change in Professional Care, Department of Social Sciences, Loughborough University.

The Family Life Committee is a Sub-Committee of the Board of Mission and Social Responsibility of the Diocese of Leicester. Its remit on behalf of the Board, is to support Christian family life and to address issues of concern from this perspective. The problems faced by young carers have been selected as one such issue of concern for the Committee in 1995.

The Young Carers Research Group at Loughborough University conducts applied research and policy evaluation concerned with young carers. It has been at the forefront in raising awareness of young carers issues in Britain and Europe.

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Published by the Young Carers Research Group, Loughborough University in association with the Family Life Committee of the Board of Mission and Social Responsibility, Diocese of Leicester.

ISBN 0 907274 15 3

£1.00 (includes p&p)