my child, my carer

~ the parents' perspective ~

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Jo Aldridge and Saul Becker

My Child,
My Carer

The Parents' Perspective

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A Companion Volume to
Children who Care:
Inside the World of Young Carers

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Foreword

My daughter's washed me and dressed and toileted me. She's sort of just been brought up with it... it comes automatic. She seems to cope remarkably well... She's not leaving home, not getting married, not leaving at all... In an ideal world I wouldn't be like this. I don't know if I'd want anyone else caring because no one else has ever done it. No I wouldn't like her to be free of caring. She's done it for so long she wouldn't know what to do with her time if she was free of it.
  Mrs Barker

I mean there were times when we couldn't even pick [the children] up when they were babies, because we were both badly ill and I was having to sort of manoeuvre them with my arms, rather than pick them up with my hands to change their nappies and I suppose if they were normal and we were normal we wouldn't point that sort of thing out to them, but sometimes you have to tell them this is the hardship we went through to bring them up, and now it's their turn perhaps to reciprocate.
  Mrs Mirza

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... We've had a hell of a couple of years with adolescence and I haven't been able to cope with her very well. But I think it's been made more horrific because of the circumstances. Well all you get told is it's normal adolescence, which it might be normal in other children, but I don't think it's normal in her. I mean the pressure she's had put on her. I mean I'm very surprised that she hadn't turned before she did, but the thing is at her age she's turned on me, I don't mean physically, but any verbal abuse I'm getting it and we've had a couple of years, it's been horrific.
  Mrs Hunter

Introduction

Background

This study is a follow-up to *Children Who Care: Inside the World of Young Carers*. In the original work we examined the lives, experiences and needs of children (under 18) who were providing primary care for a sick, disabled or elderly relative in the home.

The results of the young carers research were surprising in many respects. We found that children were performing a wide range of caring tasks for their parent/s (ranging from basic domestic duties to very personal tasks such as toileting, bathing and dressing) and that the effects of such caring responsibilities on children were far-reaching in terms of their physical, educational and psycho-social development. (Many of them were missing a considerable amount of school in order to provide care for their parents and had restricted social lives and career opportunities as a result of their caring commitments).

It was also evident that these children were consistently neglected by both family and friends as well as formal professionals who are paid to care. Finally, we discovered that their needs as young carers were modest but clear - child carers, amongst other things, wanted 'someone to talk to', someone who they could trust to tell about their concerns and fears, who would understand the nature of the caring commitment, and who would support them in confidence.

The young carers research was innovative in that it analysed, in detail, the lives of child carers and brought their condition to the attention of professionals and service providers who hitherto had neglected and overlooked them both as children *and* as carers. Previous research had focused on statistical analyses, providing 'ball park figures' of the numbers of primary young carers in the country. *Children who Care* was the most up to date and detailed study yet available on their quality of life, experiences and needs.

At no point, however, were parents or the 'care receivers' included in the original young carers research. Although the benefits of talking to them at a future date was all too clear from the outset, resources did not allow us to investigate the parents' perspective.

My Child, My Carer

It was clear from the initial research that no one had spoken to the children before about their experiences or their caring roles. But equally, no one had ever approached the recipients of their care (parent/s, grandparent/s, sibling/s) to ascertain how they felt about their children (or brother/sister) undertaking the main responsibility for their physical and emotional well being. Thus, we were especially grateful that Joint Finance (Nottingham Health Authority, Social Services and the voluntary sector) afforded us the opportunity to talk to the care receivers by financing a follow-up study to the young carers research, enabling us to obtain a fuller 'caring' picture. The findings reported here help us to better understand the feelings and pressures on parents who are cared for by their own children. They also add to our understanding of the experience of children who care, in particular, why they become carers and why they stay carers.

The primary intention of the follow-up study was not to focus on the personal

concerns and problems of the adult care
receivers as sick or disabled members of the
community, but primarily *their experiences as
the recipients of their children's care.* The
intention was to determine what the parents
of the young carers featured in the first study
felt about their child/ren's role as carer/s,
and their understanding or perceptions of its
effects on their children, and on themselves.
Furthermore, we wanted to identify key areas
of need, both in relation to the care receivers
themselves, and what they felt were the needs
of their children.

This report is intended to be a
companion, complementary volume to the
original report, and should be referred to
alongside *Children Who Care: Inside the World
of Young Carers. My Child, My Carer* is the
result of a four month study focusing on the
accounts of 10 care recipients from the 15
original families. It has not been possible to
return to all the families in the first study as
some of the care receivers have since died, or
have been hospitalised. The findings are
once again based on the oral accounts of the
adult/care receivers. We are grateful to the
families for letting us into their world, and for
giving us their perspective on their children,
their carers.

Methodology

Report Structure

In the following chapters we examine the experiences, needs and lifestyles of young carers *as perceived by the recipients of their care*: sick, elderly or disabled parents.

First, we examine the networks of informal and formal support available to the care recipients and the impact of such support on their lives and on the lives of the child carers. Next we look at the effects of caring on children as perceived by the parents/care receivers. In Chapter three we look in detail at the caring relationship - the bonds that unite the parent and child in a caring situation and the difficulties that might threaten that relationship. Finally, in Chapter 4 we talk about need - the needs of both care receivers and those of their children, both as children *and* as the informal providers of care in the community.

Many of the methodological issues and concerns prevalent in the initial young carers study were not encountered in this research project. The multi-disciplinary steering group continued its support and advisory role, but its capacity in providing key contacts in identifying subjects for interview wasn't necessary as the subjects were already known (this naturally reduced the time spent trying to identify and locate subjects for interview). The literature review on young carers had already been conducted, and it was not necessary to publicise the research in order to establish and develop a list of contact names for interview purposes. Neither was it necessary to interview professionals in the field. In short, the interview subjects (parents/care receivers) were already known, the relationship between the families and the researcher established and the foundations set for a return visit to collect the qualitative data.

Interviews with the Parents/ Care Recipients

Once again, none of the interviewees refused to take part in the research, and the families' co-operation in relation to the previous research study provided the opportunity for the researcher to return to talk to the parents/care receivers and to disseminate the initial research findings (i.e. *Children who Care*) once the interviews had taken place. Although none of the subjects refused to take part in the research, some of the parents did refuse a taped interview. This had not previously been a problem when interviewing the children, but some of the parents were reluctant and wary of a tape recorder and microphone and as a consequence written dictation was necessary.

Interview Environment and Schedule

Wherever possible the subjects were interviewed alone in their homes on a one-to-one basis. An interview schedule was once again drawn up and used as a reference point to guide rather than dictate the flow of conversation. However, the questions asked were based on key themes which had emerged from the original study, such as how the parents perceived their child/ren managed in the provision of care and how they felt about their children providing that care. We also focused on the effects of caring and explored such issues as the silence of children, as well as the parents' own personal feelings about whether children should *have* to care and if not, what the suitable alternatives were. Furthermore, as one of the

major issues to emerge from the initial study was the demarcation line between acceptable and unacceptable caring responsibilities, this was a key area identified for exploration among the adults. Thus, to a large extent the issues and themes thrown up by the first study helped to dictate the schedule for this second research project and the transcripts of the care receivers' accounts were coded and analysed on the basis of these themes.

There was no intention prior to the interviews taking place of trying to verify (or otherwise) the accounts of the children with those of their parents/care receivers. Rather, the aim was to treat them as separate and valuable accounts in their own right. Interestingly, however, there were no discrepancies in the accounts in terms of the caring biographies and the caring sequence. The parents' statements fully supported the accounts given by their children in *Children who Care*. But they also gave us valuable insights and perspectives which were not available from the first study alone.

It is important to mention here that although the interview subjects had not been sent the report of the original research (as we did not want to influence their interviews) some of the parents had prior access to the findings either through professionals (one adult had been shown the report by a social worker) or through the extensive publicity surrounding the initial findings. This was an inevitable consequence of the interest caused by the initial young carers research, but only one interview subject was aware of the contents of the report, some of the other parents had 'seen something on the TV about it' but were no more specific than this.

The Interview Subjects

There were fewer interview subjects involved in this study than in the initial young carers project because some of the parents were unable to communicate (for example Debra's mother who had Huntington's Chorea couldn't communicate effectively and had been hospitalised) or because they had since died. Thus, the total number of parents/care receivers interviewed was ten and included only two male care receivers (the majority of care receivers in the *original* young carers study were also female). As a point of interest, four of the care receivers were suffering from multiple sclerosis, one was undiagnosed but immobile and five had arthritis, coupled with other illnesses. All but one of the parents were living on benefits. Their ages ranged from 35 to 70 and two of those interviewed were now cared for by adult carers (who had been caring since childhood).

As we have already said there were few discrepancies between the accounts of the children and those of the adults and this was especially the case as far as the caring biographies were concerned. However, adults were sometimes imprecise and uncertain about the exact age of the children at the onset of care (just as some of the children had been) especially in those cases where the children had been caring for a considerable amount of time. Clearly the parents/care receivers were more knowledgeable about the onset of their illness or condition, but this did not necessarily mean they knew a great deal more than their children about the nature of their condition (a point we will examine later in Chapter Four).

All the names used in this report are pseudonyms, to protect the identities of the families.

Networks of Informal and Formal Support

<div style="text-align:right">**1**</div>

Introduction

It was felt imperative to examine the impact of informal and formal support in relation to the adult care receivers for several reasons. First, the children themselves talked considerably about the support available to their parents (as opposed to support for themselves) and second, because it was clear from the initial study that children as carers were neglected both by informal supporters (members of the extended family, neighbours and friends) and by professionals paid to care. We wanted to determine the parents' view in relation to this neglect, and their perceptions of professional attitudes to their children, as well as examine the nature of the relationship between the adult care receivers and other supporters aside from their own children.

Informal Support

It was soon clear from the research that few members of the extended family, neighbours or friends offered their support to the care receivers. This confirmed the children's accounts in the initial study that support was not forthcoming, either for themselves or for their parents, from any informal network of supporters, friends or family members. However, perhaps the most striking feature was the lack of help from male partners when their spouse had fallen ill or had been diagnosed with a particular medical condition. Half of those interviewed for this study had a partner but either they were no longer living in the family home, refused to take part in any caring commitments or had left when diagnosis occurred:

He [husband] lives locally, but he doesn't

bother and I think my illness is why he went away. I couldn't ever imagine him ever pushing me in a wheelchair.
    Mrs Barker

Mrs Barker's observation is not uncommon. In our original study we found that children were more than willing to excuse the lack of support from their fathers or other family members. However, in the follow-up study the mothers/female care receivers were certainly less forgiving and more realistic, or even critical about their partners' unwillingness to provide care:

Yes, the useless being. He'd no more pour a pint of beer over his head than look after me. He doesn't help, definitely not. I don't think he ever got the idea that I couldn't do it, you know, he'd ask me for this and that and to do this and that and I just couldn't do it, you know and he didn't seem to realise that I wasn't able to do it. He'd still ask me for this and that and where's this and where's that and I'd say how the heck do I know, I'm sitting in a wheelchair all day, how would I know? But he still doesn't seem to have got used to the idea, but he can definitely see me like this.
    Mrs Dunston

Although in the above instance the husband was still living in the family home, he refused to participate in the provision of care and left his wife alone most evenings. In the first study we discussed the notion of the 'election' of a child into the caring role by other family members and this was certainly

reinforced here. It was clear that many of the fathers had 'elected' a particular child into the caring role. This was done in several ways, either by the male partner's sudden absence when their wives were diagnosed, or by their refusal to care in the family home, either way, leaving their child/ren little option but to take on the caring responsibility. Other, more subtle methods were also employed by the fathers, such as bribery or cajolery. Mrs Walton explained that her husband had said to their daughter: 'If you look after mum, I'll look after you'. Another father, although living in the family home and carrying out certain domestic duties, had 'elected' his youngest daughter to carry out personal or intimate tasks such as showering and toileting his wife by suggesting that only she could do these tasks. Certainly, there was a gender discrimination in operation concerning caring and what male members of households clearly considered to be 'women's work'.

It was difficult to pinpoint exactly what motivated the male family members (especially the husbands/partners) to behave in such a manner. Although traditionally carers have tended to be women, this does not explain why husbands/partners are so willing to leave their families or neglect their caring duties once their wives become ill or disabled. Certainly we found no evidence of a woman deserting her husband when and if he became ill. It did seem apparent, both from the children's responses in the initial study and from the wives'/female care receivers' responses here that some husbands have difficulty facing either their wives' illness or the prospect of a long-term caring commitment. However, only by engaging the

fathers themselves in discussion would we be able to determine *their* reasons for denying or refusing any sort of caring commitment.

In terms of members of the extended family, the picture was a similar one. A recurrent theme that emerged throughout the interviews was the notion that the families 'kept themselves to themselves'. Nor did they call upon blood relatives to provide informal care. Indeed such family members had often abandoned or neglected the care receivers:

> *I've got one sister, but I don't have anything to do with her and my in-laws don't even know we live here. They don't bother with us. I'm still waiting for a sister-in-law to come and visit and she said she would three years ago. They never really bothered with us.*
> Mrs Walton

There were other issues involved here relating to cultural differences. In one of the Asian families where two boys were caring for both parents, the father had explained that different cultural attitudes meant it was considered 'unacceptable' for boys to carry out domestic or caring responsibilities and that the extended family had abandoned them, not just because the two sons were undertaking caring duties, but because they found the family's (caring) situation and the illnesses involved, difficult to come to terms with:

> *We've found that having been ill like this they sort of keep away from you, whereas in the early days when we were able to offer them a meal or something or make them a cup of tea every time they came*

*and we used to get a lot of visitors, but
now we're not feeling well we say to
somebody if you fancy a cup of tea get up
and make it sort of thing and because of
that people keep their distance.*

  Mr Mirza

This coincides with earlier findings that
people - even family members - tend to shy
away or avoid illness and any sort of
commitment to families where illness or
disability is present. Perhaps because they are
wary of becoming involved as they're
uncertain of the level of commitment they
may have to give. Or perhaps simply because
they do not want to commit any time to a
family that so clearly *needs* help.

Some of the adults or care receivers were
also unwilling or reluctant to involve
neighbours or friends in their lives. There
were clearly many difficulties involved in
accepting outsiders into the caring
environment and, furthermore, in accepting
their support in terms of the care receivers'
particular caring needs. However, it did seem
that, over time, adults (as opposed to
children) were more willing to accept
neighbours into their homes to lend support,
albeit of a social rather than a practical or
emotional nature. Some of these neighbours
had become involved during a crisis point in
the care receiver's life and had remained
friends. However, it seemed to take some
considerable time before a trusting
relationship could be allowed to develop and
more often than not, in that time the
neighbour would move away - the 'transience
of residency' was clearly apposite here, and
often when a trusted neighbour/friend did

move away their friendship was never
replaced. Two of the care receivers said they
had good neighbours or friends in the past,
but once they had moved away that had been
the end of the friendship and their support.
These care receivers were literally 'trapped'
within their homes through disability or
illness, and economic deprivation.

The nature of support offered by
neighbours and friends was not, as we have
already suggested, of an emotional or indeed
practical nature (i.e. carrying out caring
tasks). There seemed to be a tendency within
the families not to involve friends and
neighbours in the actual caring routines.
Neighbours and friends generally used to
'come in for a chat' especially when the care
receivers were alone. As Mrs Dunston said of
her friend and neighbour: 'Well she never
helped much but she always came in for a
chat'. There was however, a definite intention
to keep their support purely on this type of
social basis as opposed to practical care
provision or emotional support, as Mrs
Barker explained:

*If my daughter must be replaced as a
carer then it would have to be by a
professional, not a friend. If it was a
friend you lose the friendship. You rely
on friends to be friends, not to be useful.*

Or Mrs Winterbottom:

*I'd sooner the children do the caring than
anyone else. Sometimes neighbours and
friends come in if they know I'm on my
own, not really to help, but to see if I'm
all right.*

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As we have already highlighted, it takes some considerable time before adult care receivers will trust potential informal supporters and in that time these helpers could have left the neighbourhood. Often, because of their immobility or stasis, any support the care receiver might wish to draw on would have to be from the immediate neighbourhood. This could be one reason for the lack of support from other family members as, more often than not, they lived outside the neighbourhood. Some adult respondents suggested more selfish motives for why family members and neighbours/ friends were reluctant to involve themselves, certainly in any long-term caring commitment. For example, Mr Mirza talked about the increasing self-interest in society:

> *I don't think there's many people who go out to do favours for neighbours or for anybody else in the community because everybody's sort of money motivated.*

What is interesting is that although adult care receivers seemed reluctant to involve outside informal helpers in the caring routine, they were more than willing to allow their children to undertake many caring responsibilities, some of which were of a very intimate and personal nature. This seemed to be based very much on the idea of 'keeping it in the family' - a reluctance to go outside the family for help through pride and fear (adults are also afraid of the consequences of bringing in help, especially from professionals. We will discuss this further in Chapter 2) even though the effects of caring on the child/ren may be extensive and complex. Thus, it appeared that what was considered to be unacceptable caring involvement from other adults, was more than acceptable for their own children. However, within the child caring environment there were clearly divisible lines of 'acceptable' and 'unacceptable' responsibilities, and again we will discuss this further in Chapter 3.

Formal Support

It was clear from the initial study and indeed from this follow-up research that several families were receiving formal support from professionals paid to care, but that these services were aimed entirely at the needs of the care receiver. Furthermore, two other observations from the initial study were confirmed: at no time did these professionals engage the children in any discussion or conversation about their caring roles or needs as carers; and services had been withdrawn when the professional concerned (for example, Community Care Assistants, CCA) deemed the child a 'suitably responsible age' to adequately manage the provision of care. The accounts of the parents/care receivers confirmed both these points.

Across the range of professional support, from CCAs to nurses and GPs, it was clear that the adult care receivers felt that at no point had their children been involved in discussions about their caring responsibilities or their own needs, nor indeed had they been informed or advised on care management issues:

> *Doctors don't talk to kids, they didn't talk to my daughter.*
> Mrs Barker

Or Mrs Winterbottom:

*They don't ever talk to the girls about
caring. The nurse comes round
occasionally and the health visitor and
they all know my daughters care, but
they've not said anything about it
though.*

*I feel very angry that she's been left.
She's had no help from the services and
no back up, no nothing. I mean a couple
of incidents that I could tell you about
when I eventually went to the doctor and
asked if he would explain my illness to
her, I was politely told that she would
have to learn to live with MS. Nobody
bothered her, nobody took her to one side
and tried to talk to her. There's nobody
done nothing either physically or
mentally for her.*
    Mrs Hunter.

Interestingly, although some of the adults
expressed surprise or anger over the decision
to withdraw community care assistance once
their children were considered 'old enough'
to care (anything from 12 to 16 years of age),
the majority of them accepted the decision
and didn't question it or seek any further
support - or indeed a second opinion - from
social services. In fact, several of the parents
were remarkably understanding and
philosophical about the lack of, or reduction
in, professional support. Some of them even
suggested that they understood because
'there were a lot of other people worse off
than us'. Mrs Mirza highlights this attitude of
acceptance:

*They just said they couldn't spare the
help anymore because they thought the
children would be able to cope...this is
going back nearly three years, so the
eldest one must have been about 12 and
the youngest was about nine...but we
don't like to put too much on the
youngest one, he suffers with asthma.*

The lack of consistency, or the apparent
'arbitrary' nature of professional help (and its
withdrawal) was highlighted in the initial
young carers study and was again mirrored
here in the adults' own personal experiences
as the recipients of professional care. Unlike
the children, however, many of the adults
were aware of, and able to distinguish
between, the various professional services,
and were more able to highlight gaps in
service provision. Although it was clear from
the earlier findings that adult *carers* enjoyed a
better, certainly more autonomous,
relationship with professionals, it was not
necessarily the case that the care receivers'
relationships with professionals were either
good or even satisfactory. Part of the conflict
between the care recipients and professionals
was caught up in the division between the
informal provision of care from the child/ren
and the formal care provided by
professionals. For example, a few adults
suggested they were dissatisfied with the
community care assistance they received
because their children didn't like the CCA
coming into the house, and in some cases the
children had told their parents that the CCA
had been 'interfering in their things':

*I stopped the CCAs going upstairs
because they were going through the kids'
things. I didn't catch them at it, but we
knew from what had been moved that
they did it.*
      Mrs Winterbottom

This notion of 'interference' also related closely to the conflict over duties - the differences of opinion over which household or caring tasks took priority. Indeed, a successful relationship between the care receiver and professional seemed to depend on four factors:
* no conflict between the formal professional and the child carer;
* accordance over tasks - the client and the service provider must agree on what tasks need doing and which are priorities;
* personality compatibility - a relationship of trust must be established;
* consistency and duration - the length of time the individual professional had provided caring assistance was very important in order for the client to become 'accustomed' to them and their regular presence in the home.

Where the family is Asian then these factors take on added importance. The last two factors are closely linked. Clearly, it takes time for a relationship of trust to develop and for the client to accept a paid professional into their home. But developing trust also depends on the professional's ability not to conflict with the child as carer. Thus, even if the CCA, for example, isn't engaging the child/ren in discussions about caring and care management, there must at least be no open conflict between them, and the CCA must observe certain rules such as not to

'interfere' in the children's tasks or with their possessions, or intrude on the child's domain (such as their bedroom). Certain ground rules it seems must be established and observed. Mrs Winterbottom, for example, was very hostile towards her 'home help' because the home help was inconsistent in her time keeping and did not relate well with her daughter:

*I used to get home help but sometimes she
came and sometimes she didn't. When my
daughter was here and the home help
came she wanted to know why my
daughter was at home and said 'oh if
she's at home I needn't come in then'.*

Furthermore, the clash of interests, especially relating to domestic duties, seemed to be a major problem in the relationship between client and professional care provider. The client has one idea of what he/she wants doing in terms of care provision, and the paid professional might have other ideas. Mr Mirza commented:

*We used to have a home help for a couple
of hours a week, but they always wanted
to go out to do the shopping for us - that
was a job the children could do... there
was a dispute over what we wanted them
to do and what they thought they were
here to do, so perhaps disagreement if you
like over the terms of reference. I mean we
thought they were here to help us to do
the things we couldn't do, they thought
that they were here to do other things.*

Or, as Mrs Hunter said:

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.

In terms of professional care provision, part of the problem seemed to be that there was little *choice* available for the client. The care receivers are assigned professionals to care for them regardless of the aforementioned factors such as personality compatibility, accordance over tasks etc., and there did seem to be some conflict over the services on offer and what the client actually *needed*. This dispute was particularly marked in the Asian families where, for example, Mr Mirza's expressed needs were not necessarily met by the CCA, who chose to do other things for him instead. Although it is unlikely that social services would engage in 'matching' clients with individual professionals to ensure compatibility (including compatibility in terms of race, religion or culture), it would, it seems, go some way to improving care recipient/care provider relations if the *needs* of the care receiver were observed or if services could be made to be more flexible. In the Asian families the lack of religious/racial compatibility, the lack of cultural understanding, and the disregard for the families' expressed needs was particularly pronounced.

When the factors for a good working relationship between client and service provider did combine, formal care provision seemed to work well. Indeed, some of the adult care receivers had adapted to the nature of formal care, which seemed to complement the informal care they received from their child/ren. Some of the parents enjoyed a 'reasonable' relationship with the professional carers. For example, although Mrs Dunston had previously had bad experiences with professional help - 'some of the home helps you got, they were hopeless' - she had since become friendly with the nurse who had been attending to her for some years, as she explained: 'I get on with the auxiliary nurse, she's been coming years now and I know her pretty well'.

However, all the parents or care receivers said that their children were better carers than the professionals who were paid to provide care. Even though the children might have been very young, and even though, in principle, the parents might not agree that children should *have* to provide care for them (we will discuss this further in Chapter 3) and were often performing tasks they thought to be 'unacceptable', all the adults preferred to be cared for by their children as opposed to outside help or paid professionals. This preference may be bound up with the power relations within a parent-child, cared for-carer relationship. Children are easier to control than (adult) outsiders (we will also be discussing issues of control later in Chapters 3 and 5). But the rationale behind this preference for children to care also seems to be located in the bond between care recipient and care provider - in the very nature of the caring relationship (again, see Chapter 3).

Some of the adult care receivers were aware of the 'political' aspects involved in formal care provision. Indeed, some were

aware of the changes in practice brought about by the movement from the old 'home help' system to the new community care assistant provision, and that most local authorities were unable to provide suitably flexible professional care from an already over stretched (under resourced) service:

> *You know the home help system as it is it's far too stretched to do any good, or to get any sense out of it, they've got far too many clients.*
> Mrs Hunter

Or, as Mr Mirza stated:

> *The last time we moved they said they had such a large area, such a large work load and so few people that they couldn't really do anything for us, especially since it changed from home help to community care - the job description, just by changing the title of the job, changed also. I mean I don't begrudge them, they deserve respect for what they do, but you shouldn't get away from what the client needs. I think there's been a greater difference between need and supply since the change in that sense.*

Conclusion

Clearly children as carers are being overlooked and neglected by both informal supporters and professionals who are paid to care. Elsewhere, we have defined this as 'punishing children for caring', or indeed, the abuse of children for caring (see *Children who Care*). However, although adult *carers* may enjoy better relations with professional care

providers, this is not necessarily the case as far as care *recipients* are concerned. There are many conflicts between client and service provider - problems relating to disagreements over task performance and priority, as well as problems with consistency and personality compatibility. Furthermore, as we have seen, conflict can arise when the security or happiness of the child carer is threatened by professional intervention. What appears to be required is a greater public and professional understanding of the problems involved in families where children are carers, and where long-term parental illness or disability is present; agreement between care recipient and (formal) service provider as to what 'need' actually is, and which needs can be met; and greater flexibility and sensitivity in the delivery of services, including responsiveness to race, religion and culture.

The Perceived Effects of Caring on Children 2

Introduction

Although in our initial study we were able to determine the primary effects of caring on children, in this study we also wanted to ascertain these effects *as perceived by their parent/s or care receivers*. Interestingly, when asked a general question about what they considered the main effects of caring on their children to be, the parents seemed unable to answer. This was an issue that few parents had either considered or articulated. However, once the interviews were underway, it became clear that although they didn't highlight the specific effects of caring as such, they talked at length about their own and their children's silence - the children's reluctance to talk about their caring responsibilities and the conditions at home; about their school and social lives and about coping with caring. In the following pages, we will be exploring these issues in turn.

The Silent Children

Without exception, all the parents recognised that their children did not talk about their caring responsibilities to anyone, either their friends or professionals. The majority of parents said they thought their children did not *want* to talk about their caring experiences, although few of them gave any reasons for this other than they just wanted to 'keep it in the family'. Interestingly, considering that 'talking to someone' was a primary need highlighted by *all* the children in the initial study, none of the parents seemed to be aware of this need. The parents seemed quite unaware of any problems or worries the children may have had, and as a consequence thought them more than capable of coping

with their caring responsibilities (we will be discussing this further in Chapter 4).

It was clear that at times parents actively encouraged their children not to talk to others about their caring roles, because of some sort of notion relating to 'family pride'. Indeed, there was a definite emphasis on keeping caring and family issues private, as Mrs Walton said: 'We were never ones to mix much, we sort of kept ourselves to ourselves'.

It was also clear from the parents' responses that children had kept silent about any fears or any pressures relating to their caring roles (indeed most parents didn't even know what their children liked or disliked about caring). This could have been because many of the children's concerns seemed to be entirely related to their parents - to fears and anxieties about their parents' welfare. It may also be the case that parents don't really want to acknowledge their children's caring problems because it may only serve to emphasise and exacerbate their own pain or guilt over having to receive informal care from their child/ren.

Just as the children were 'silenced' by the caring role, the parents were equally reluctant to divulge the fact that their child/ren were caring for them. Although parents were willing to discuss with professionals their own needs, they were not willing to discuss their child/ren's needs as carers, especially when the children were very young. Furthermore, it seemed that the same fear that motivated children to remain silent about caring also affected the parents - the fear of the professional response; that the consequences of telling might lead to the eventual splitting-up or separation of the family:

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

Or, Mrs Barker:

Disabled people hide it because they're frightened of losing their kids. I didn't contact any professionals because of that.

It was apparent that this threat was only removed once professionals involved in the families had recognised the fact that informal care was being provided by a child or children in the home, and that these professionals had 'legitimised' the child caring role by suggesting families could manage without outside help because the children were 'old enough' to care. We have already seen from the findings of the initial study that this 'old enough' criteria varied enormously. The child/ren might not have seemed 'old enough' to care as far as parents were concerned, but this 'seal of approval' from those in authority seemed to reinforce - or enforce - the children into a role as sole carer. Clearly this may also have serious implications for the control that parents may then exercise over their child, their carer.

Coping with Caring

As we have already indicated, the parents seemed convinced of their children's ability to cope with caring tasks and responsibilities. Although there may have been a natural reluctance on the part of the parents to talk openly and honestly about the children's lack of ability to cope (for fear of the consequences), it did seem that parents were genuinely convinced their children coped well with their caring roles. A recurrent theme was the notion of children taking caring 'in their stride', as the following examples illustrate:

Well I think they cope reasonably well because we've brought them up to understand the values of family life.
  Mrs Mirza

Well she just takes it all in her stride, she doesn't grumble much, anything much about it or anything, you know.
  Mrs Dunston

She seems to cope remarkably well.
  Mrs Barker

Even in those instances where the onset of caring had started from a very early age, and even when the children were carrying out personal or intimate tasks, the parents were assured that their children coped well, even with those potentially embarrassing tasks such as bathing or toileting (especially when such responsibilities had started at an early age - this reinforced the notion of children being 'socialised' into their caring roles):

*My daughter's washed me and dressed
and toileted me. She's sort of just been
brought up with it and even my
granddaughter watches me while my
daughter puts cream on me 'down there'.
You're there and it comes automatic.*
  Mrs Barker

Again it was clear that regardless of what
the children might feel about providing care,
the parents were genuinely unaware of
problems connected with caring among their
children. However, it may also be the case
that they did not want to admit there might
be problems. Either way, the children were
the ones left to cope with caring alone, and in
silence. This isolation is further reinforced by
the neglect of children by others outside the
family and caring environment. Indeed, from
the initial young carers research it was clear
that even when confronted with the issue,
certain professionals suggested that caring
among children was legitimate as long as the
children were 'happy to care' (even if it was
of a very intimate and personal nature).
However, we found no evidence of children
who were 'happy' in the intimate caring role -
there is a considerable divide between
'happiness' and adaptation or resignation.

Thus, we can see that if the professional
response is neglect - the failure to delve
deeper into the child caring experience (to
determine exactly what the child carer feels
about the provision of care, from basic
domestic duties to personal tasks such as
toileting etc.) - then the children are placed in
a very difficult situation. They are isolated
and have to cope alone, not only with caring
and all its effects, but also with their own

fears and anxieties. They are left with no
choice in undertaking care in the first
instance, and extending it into an uncertain
future in the second. In spite of all this,
children continue to care and display a
remarkable commitment to the caring role,
regardless of their distressing or painful
circumstances, and regardless of the nature of
the duties they have to perform.

Life at School
Most of the parents said they didn't and
wouldn't keep their children from school in
order to carry out caring duties at home.
Indeed most parents were adamant that their
children had never been late or missed school
due to their caring responsibilities. However,
we were unable to interview the parents of
those children who, from the initial study,
had taken a great deal of time off school
(these parents had since died or had been
hospitalised). It is questionable whether many
of the other parents would admit to keeping
their children off school anyway, for fear of
the repercussions from the education
authorities. As we have seen in the previous
chapter, the fear that the family might be
split-up by professionals was a very real one.

However, Mrs Winterbottom for example,
was very open about her daughter's absence
from school. Mrs Winterbottom needed her
child at home because she could not cope in
the day time without care. But, like many
other recipients of informal care, the problems
tend to become cumulative. For example, Mrs
Winterbottom was immobile and needed help
up and down stairs throughout the day and
night to the toilet and her bedroom. There
was no one else to help but her daughter.

On many occasions her daughter was forced to stay home and care for her. In an attempt to solve this predicament Mrs Winterbottom had asked the education authorities for a home tutor, but had been refused because her daughter wasn't ill herself. She had also asked the housing authorities for a bungalow so that she didn't need to rely on her daughter in the day time. The council were unable to offer her a bungalow big enough. She knew that in each instance her problems would be solved if her children didn't live at home because then she could have a bungalow and they could go to school. But then she would have no carer. Mrs Winterbottom was trapped in a situation which appeared to her at least, to have no solution:

> If she doesn't go to school they said they'll take me to court, but I actually can't cope if she's not around. I asked for a home tutor but they said not unless she's ill. There's other kids don't go to school in this street and the mothers are all right. My kids are willing to help but the only snag is their schooling.
> Mrs Winterbottom

In many cases the response from parents seemed to be based on differences in the value placed on education for their children. For Mr and Mrs Mirza their children's schooling took priority over their own welfare:

> Well we give them adequate time for school work because we tell them they must do their homework first and devote a couple of hours. If we were totally selfish then obviously ours would miss

school as well and things like that but we have to say OK if this thing doesn't get done, it doesn't get done, because their future is more important. There have been times when we have felt like keeping them off but we insist they go to school.
> Mr Mirza

All the parents said that their children had never been offered any support from school in terms of their caring responsibilities at home, even though in some cases the school staff were aware of the presence of disability or illness in a one parent family and that this must place some strain on a child. Indeed, as the Winterbottom case illustrates, school authorities had only intervened when long-term absences had been noted, which confirms our previous findings that schools were not recognising or identifying young carers. Obviously if the children aren't willing to talk about their caring roles and parents are also wary of the consequences of telling outsiders, then this lack of recognition is not surprising. Only by a parent being assertive would school staff take note of, or be on the alert for, particular problems:

> I care, I wouldn't have her missing school. I think the schools should play a bigger part though. Her teachers were wonderful because I worked with them. I always went to parents' evening. I made a point of telling them, making sure they knew about my disability - they're the ones that should be helping the children. Why should it have to get to such a devastating effect before anyone pays any attention to children? But often they

*don't go to school because they feel guilty.
It did cause chaos down at school because
of access for me. One evening I was
allotted a teacher as my pusher! But
you've got to have the right attitude. I'd
rest all day so I would be on form to
tackle the staff at parents' evening.*
  Mrs Barker

Social Life and Friendships
It was clear from the findings in the initial
study that caring severely restricted
children's social activities and friendships and
that their horizons were limited because of
their caring commitments. This was also
confirmed in the follow-up research. Most
parents recognised that their children
couldn't go out like other 'normal' children
because of responsibilities in the home. It
seemed to be generally accepted among the
parents that restricted social activity was a
necessary, if unfortunate, consequence of
caring:

*It does restrict their activity socially, but
they do get out, but they don't like go ice
skating and that. One of them has to be
here though. They can alternate now. It
would be worse if it was only one child. I
do try and let them have a bit of free time,
but free time they have is only outside the
home and they can't go too far.*
  Mrs Winterbottom

*I'd like to see her [daughter] with more
freedom than the whole time caring for
me you know. But if she does go out at
night or anything I'd have to sit on my
own here and you know I get a bit lonely*

and that.
  Mrs Dunston

In some cases parents had been forced to
prioritise activities for their children. Parents
made a choice between what they felt was
important and what was less important for their
children's well being. They had decided school
work took priority over any kind of social
activity. For example, Mr and Mrs Mirza had
decided the boys' school work was more
important than socialising and this had
restricted their sons' social and leisure activity.
These decisions were made without the child-
ren's consent or without conferring with them.
By prioritising tasks and the general structure of
their children's lives, parents exercised control
over their children/carers. So, on the one hand
the children cared for their parents and saw to
their daily welfare, but on the other hand
parents still tried to organise their children's
lives by exercising control over them:

*If they have to do something for us then
they obviously have to miss their
television watching time, which we don't
encourage very much anyway, but as far
as social is concerned we don't encourage
them to go out and hang out on street
corners because we feel that's wrong, but
they have friends they go out if they want
to go out and play cricket or football we
always let them, we encourage them to go
out and play as long as they ...there are
certain jobs which they have to do like
stacking the dishwasher at the end of the
day or after meals or taking the dishes out
again, things like that.*
  Mr Mirza

As the above example illustrates, parents also dictated the nature and extent of their children's social activity (in this example sporting activities were sanctioned, general socialising was not). However, interestingly, what did *not* emerge from this research was the notion of the 'caring curfew', that once the children were allowed time to socialise, parents were placing time limits on such activity. There was no acknowledgement of the parents' efforts to restrict (time wise) their children's activities outside the caring environment. It was apparent from the initial young carers research that, as far as the children were concerned, their parents tried to control their lives outside caring by restricting their time out to one or two hours. Some children also referred to less overt, more subliminal methods of control, such as their parents creating more work for them when they returned from socialising. The parents presented a different picture.

Parents would often speak on behalf of their children or suggest that their children didn't want to go out much - that, by implication, they would rather stay in and care for them. This was another form of parental control - talking *for* their children, assuming that what they (the parents) wanted also coincided with their children's needs and what the children wanted to do. For example, in the original young carers research, Mrs Walton's daughter Sally said that she had often wanted to stay out later than the time of the last bus home, but she couldn't because her mother didn't want her to. However, her mother told us:

She didn't have all that many friends. She had boyfriends and used to go dancing a bit on a Saturday as she got older. But she has never really left me since the day she was born, she was never really that type to want to stay out late.

Such discrepancies and intentions on the part of parents to speak on behalf of their children - assuming and presupposing their wants and needs - emerged in other areas too (which we will be discussing later), and could be indicative of the fact that parents need to be reassured that their children want what they want. This is perhaps based on the fear of loss of control over their children's (and to some extent their own) lives, or indeed the fear of removal or cessation of care provision by their children - that they might at some point leave the caring environment. This is further reinforced when we consider that the parents said they would prefer their child/ren to care than anybody else (see Chapter 3).

Some parents had tried to make an effort to lessen the strain on their children's lives by 'making the best of things' and trying to incorporate their social activities and friendships into the family home or the family environment. Mrs Barker, for example, suggested that all disabled/sick parents who needed care from their children should make an effort to encourage friendships and socialising:

You've got to make the effort, if she can't go out then her mates come round here. You have to make the extra effort because you know they need friends and you have to make the effort for them. Most disabled

people have got the chance to make a
decent life for their kids.
    Mrs Barker

However, this is not always feasible nor always welcomed by the children concerned. They don't necessarily want their entire lives to revolve around the family home. Children saw it as important to 'escape' or have a break from the caring situation from time to time, but again this 'need' was not really addressed by the parents.

Conclusion

It is clear both from these findings and from our previous research findings, that the effects of caring can be many and complex. However, generally parents had clearly not examined the impact of caring on their children and were less able to articulate them than were the children themselves.

However, similar themes emerged here as in the initial survey. The parents confirmed their children's unwillingness to talk about their caring experiences outside the caring environment. It was also evident that child caring also affects adults in relation to their own unwillingness to disclose their caring circumstances. Furthermore, it was noticeable that parents attempted, to some extent like parents do, to control their children's lives, further exacerbating the strains on the children and on their silence as carers.

It was also clear that parents were less likely than the children to open up or talk candidly during interview. In the initial young carers research the children openly discussed their experiences, needs and fears and indeed, in some cases, said they had

found the interview experience therapeutic. However, the parents were perhaps somewhat more wary of talking openly to strangers. Arguably this has less to do with the 'innocence' or openness of children and more to do with the many complex issues involved for adults/parents who are forced to be the recipients of their children's care. Certainly parents seemed conscious of the potential implications of 'telling all' - the fear of how certain aspects of their lives and conditions would appear to outsiders (a greater fear about 'what people might think'), the fear of being judged, the fear of the family being split-up, and also the constrictions of their own emotional uncertainties - the guilt and fear connected with receiving care from their children, aspects of which we will be discussing in the following chapter.

3 The Caring Relationship

Introduction

Evidence presented in *Children who Care* suggested that caring had brought both carer and care receiver closer together, especially where the relationship was on a one-to-one basis (i.e. there was no one else available to care). This was also confirmed in the follow-up research. However, the picture from the parents' perspective is profoundly complex and emotionally charged.

Parental Guilt and 'Intimations of Normality'

Parents certainly seemed to be suffering many emotional concerns relating to problems and fears concerning the parent/child relationship. However, during the interviews parents *said* that their relationship with their child/carer was generally a good one:

> She's done very well over the years. I don't know what I'd have done without her. We have our arguments and ups and downs like everybody does but there's a very big bond between us.
> Mrs Walton

However, there was clearly much underneath the surface, in the division between parent-child and care receiver-provider relationship. For example, many of the parents admitted that they had arguments with their children, but then tried to qualify this during interview by denying the significance of disputes; by suggesting 'they were nothing'. In some cases there did seem to be a fear of admitting arguments took place in case they were considered by outsiders (and by the researcher) to be a sign of some deep-seated problem in the *caring* relationship, rather than just a family argument:

> Oh yes, yes, we have a good relationship. We've always been very close. Not lots of arguments. We might have one and it'll be over in ten minutes... there's nothing you could really say is an argument you know.
> Mrs Dunston

> My relationship with her [daughter] has really got better since caring. There are bad times and good times. There's never really any bad times...
> Mrs Winterbottom

The fear of being judged or of disapproval from others, or the tendency among the parents to deny problems in the caring relationship, also coincided with issues associated with guilt. It was clear that among the parents there were high levels of guilt involved in being forced to receive care from their children. Although no indication of this emerged from the initial interviews with the children, their parents either openly or covertly expressed their guilt and anxieties over the fact that their children were caring for them:

> Well we feel guilty really that... especially when they were a little younger, the eldest one is 15 now and the other one 13, but as far as we're concerned they're still children and we always felt guilty, originally with them having to attend nursery full time and we couldn't care for

them, and after that as they grew older to give them jobs, I mean I feel guilty. We feel that we've deprived them of their childhood in a way.
   Mr Mirza

Needless to say we all wish the children didn't have to care. I don't like asking her to do it, and we have the odd row. I feel guilty about the fact she has to do it. I overcompensate anyway. The question is do we put on them? and the answer is yes of course we do and then we get all remorseful and buy them a car!
   Mrs Barker

My daughter had to become a latch key kid through circumstances beyond all of our control and when you hear people talking about latch key kids and the parents, you know it makes you feel bad.
   Mrs Hunter

This guilt seemed to manifest itself particularly in questions and perceptions of 'normality'. Time and again respondents referred to 'normal family life' and a 'normal' parent-child relationship as a measure of their own individual circumstances, and this 'normality' yardstick often found their own relationships wanting. In certain cases it seemed that some parents felt 'normal' family life had been lost, both because of the presence of illness or disability and because of the fact that their child/ren had to care for them. This was clearly not helped by the fact that in many cases the parents had very little to compare their relationship with. They had either always been disabled or the child had

only ever known them as disabled, and in many cases all the children could remember was the caring relationship between them.

Parents certainly seemed to be afraid that their illness or disability might be the cause of problems in the parent-child relationship and this in turn caused them a great deal of uncertainty and distress, (although again, this was not something that emerged from the interviews with the children). Clearly, this idea of 'normal' family life was based purely on the parents' comparisons with other families where children did not have to take on caring responsibilities and consequently they seemed to be using this perception of 'normality' to punish themselves, further compounding their guilt. This was in many cases clearly leading to a great deal of self-blame. Circumstances which were, after all, beyond their control, were used as exemplars of their own familial failings, as these following examples illustrate:

There isn't support for the disabled either, you begin to wonder is it because I'm disabled that problems arise? Is she rebelling because I'm like I am? You don't look at it clearly or logically. I need somebody to sound off at because you do blame yourself - are we arguing and screaming because I'm disabled or is it normal? When you're disabled you don't know what normality is anymore.
   Mrs Barker

We've had a hell of a couple of years with adolescence and I haven't been able to cope with her very well. But I think it's been made more horrific because of the

circumstances. Well all you get told is it's normal adolescence, which it might be normal in other children, but I don't think it's normal in her. I mean the pressure she's had put on her. I mean I'm very surprised that she hadn't turned before she did, but the thing is at her age she's turned on me, I don't mean physically, but any verbal abuse I'm getting it and we've had a couple of years, it's been horrific.
   Mrs Hunter

I mean there were times when we couldn't even pick them up when they were babies, because we were both badly ill and I was having to sort of manoeuvre them with my arms, rather than pick them up with my hands to change their nappies and I suppose if they were normal and we were normal we wouldn't point that sort of thing out to them, but sometimes you have to tell them this is the hardship we went through to bring them up, and now it's their turn perhaps to reciprocate.
   Mrs Mirza

Clearly as the child carers developed into adolescent carers there were the added strains of adolescence for parents to cope with, as well as their hopes and fears for the continuation of care. Yet still the parents, as care recipients, seemed unable to distinguish such problems from the individual circumstances of being ill/disabled and having to be cared for by their children. This undoubtedly places added strain on the caring relationship, both in terms of their increased guilt and the fears about the effects of caring on the parent-child relationship. This could perhaps account for why parents tried to exercise control over their children - in an attempt to retain, as far as possible, some semblance of 'normal' family life and to gain some power where, on the whole, they were powerless.

We have already touched on this notion of control, but it was very clear that despite the fear and guilt (indeed perhaps because of the fear and guilt involved in the caring relationship) parents did try to control the parent-child as well as the carer-care receiver relationship in many ways. (This also seemed to apply when the young carers became adult carers). For example, parents would often talk on behalf of their children, presupposing their wants and feelings. They also suggested that their children wouldn't and didn't want to leave the caring environment; and assumed that what they, the parents, wanted or liked/disliked in terms of their condition was also mirrored by their children. For example, Mrs Walton was offered respite care but didn't want to take it and asked the hospital if she could stop attending. They told her such a decision had to be made by her daughter. However, her daughter clearly wanted respite care to continue and yet Mrs Walton said: 'I don't like going in for respite care and she [daughter] doesn't like me going in either. She hates me going'. Other examples of control were noted:

My children would sooner care for me than outsiders.
   Mrs Winterbottom

She's not leaving home, not getting married, not leaving at all.
　　Mrs Barker

She's not married. She says she'll never marry, no she'll never marry.
　　Mrs Dunston

Why Children Care

Another indication of the fear associated with the effects of caring on the parent-child or care receiver-provider relationship, lies in the reasons why parents think their children care for them. Although it was clear from the initial young carers study that children revealed a remarkable commitment to the caring role, despite their often painful and distressing circumstances, we wanted to ascertain what the parents felt about their children caring and why they thought they committed themselves to the caring role. Interestingly, none of the parents said their children cared because they had to, or because there was no choice or no suitable alternatives (even though the children had indicated that they were often forced into the roles, 'elected' into them by other family members or 'socialised' into them from an early age). Indeed, most parents seemed to feel that their children cared out of a sense of affection or emotional commitment, not out of duty and certainly never out of a sense of pity:

I think it's more affection than anything else because they realise the way we have been over the years. So I think it's not really sympathy I think it's more out of love.
　　Mrs Mirza

They [children] are the best people to provide the care because of love.
　　Mrs Winterbottom

Caring's not just physical, it's more than that, it's someone to laugh with, joke with, talk about the local political situation.
　　Mrs Barker

I don't know, it just came automatic I suppose. We just liked each other's company.
　　Mrs Walton

Some of the adults tried to explain or perhaps justify their child/ren's caring through some historical precedent, or to confer legitimacy on caring because of the 'tradition of caring' or societal expectation. For example, Mrs Barker suggested that 'on the continent they do it anyway, it's expected over there' or Mrs Walton: 'Things have changed a lot over the past 25 years. Once upon a time you had to look after your parents'.

The Acceptable and the Unacceptable Face of Caring: In an Ideal World...

As we have already mentioned, some discussion emerged from the initial study about 'acceptable' and 'unacceptable' levels of caring among children. The professional viewpoint varied here even within social services for example, and yet children continued to provide a range of tasks, from basic domestic duties to very personal and intimate tasks, because they had no choice - because there was no one else available or

willing to do them. However, as we have said, although some of the children had been performing tasks such as toileting, bathing and dressing their parents (tasks which varied in intimacy depending on the nature and extent of the parental condition) we found no evidence of any child who was happy carrying out such duties. They may have become *accustomed* to them over time, but they did not enjoy intimate caring.

To complete this picture, however, we needed to determine what the parents thought about the responsibilities their child/ren were undertaking. We wanted to ascertain what they felt about their own child caring for them. We also wanted to determine if they felt it was acceptable for children to be undertaking such caring responsibilities, and if not, then who they thought should be responsible for care provision.

It soon became clear that parents had strong views about the levels of acceptable care provision among children. Furthermore, the dividing line between 'acceptable' and 'unacceptable' generally seemed to be drawn in relation to intimate or very personal caring tasks, as the following examples illustrate (and once again we can see the recurrence of the concept of 'normality'):

> *I think the sort of things they should be doing is perhaps making their own beds up and things like that and keeping their own rooms tidy which I think is a normal thing for children to do and perhaps making the occasional cup of tea or something like that, that sort of thing is acceptable. But personal tasks such as bathing and toileting would be totally*

> *unacceptable to us, because that's not really children's work, I mean children obviously would do it because again they would feel a moral obligation to do it but I don't think that's a job for children.*
>   Mr Mirza

> *A child shouldn't have that [intimate] responsibility so young, even a young adult shouldn't have that responsibility. She has the right to be a normal child, to do normal things without the added responsibilities that she's got.*
>   Mrs Hunter

The parents believed that it was inappropriate for children to be carrying out such roles, even if the children felt 'comfortable' with them. Furthermore, we must also consider aspects of dignity, pride and levels of embarrassment, not only among the child carers but also among the parents as the recipients of their care:

> *What is unacceptable is those children who have to clean their parents up. My doctor put me on different tablets and I lost control and it was embarrassing and I would hate to see her doing those tasks on a regular basis. She finds it embarrassing, but I wouldn't stop her for my reasons, but if I think it's wrong I would stop her anyway.*
>   Mrs Barker

However, it is important to stress here that it seemed easier for parents to be more adamant about levels of acceptable/unacceptable caring responsibilities if their

child/ren *weren't* actually having to perform such intimate tasks. Those families where intimate caring responsibilities were necessary because there was no one else to do them, were less likely to have strong views about the line between acceptable and unacceptable roles, although it was clear that in such cases standards within standards had been established and recognised. So, for example, a child might be having to bathe and dress a parent, but within such personal caring circumstances, there were still unacceptable avenues of care, as the following example illustrates:

> *She [daughter] still has to help me. I*
> *could never have a shower when she's not*
> *in the house for example and she has to*
> *dress me, but below the waist is out of*
> *bounds.*
>   Mrs Barker

Furthermore among the parents, there seemed to be a distinction between the theory and practice of caring; between what their own child/ren should or shouldn't be doing in terms of caring tasks and between the notion of childhood and caring in general. So, for example, a child may actually be having to perform intimate 'nursing' duties, and yet still, in theory, the parent believed this situation to be unacceptable. This theme emerged time and again: the abstract concept of legitimate and inappropriate caring and the reality of child care provision in the home:

> *She [daughter] has washed me and*
> *dressed and toileted me. She's sort of just*
> *been brought up with it. It's not*

> *embarrassing. Doing personal tasks is*
> *very hurtful isn't it?*
>   Mrs Walton

> *They [children] bath me - doesn't bother*
> *us. I'm not embarrassed with family. I*
> *would be with other people. But it all*
> *depends on circumstances. It's not all*
> *right for kids to do personal things*
> *though.*
>   Mrs Winterbottom

Who Should Care? The Caring Contradiction

This notion of the division between the theory and the reality of caring also emerged when parents were asked who they thought should be responsible for care provision. Interestingly, all the parents agreed that children should not have to provide care and yet, in truth, the relationship between themselves and their children as carers was clearly crucial to their well being. There was a big difference between who *should* care and who they *wanted* to care. Many of the parents had little choice but to accept care from their children, and some, like Mr and Mrs Mirza, were quite aware that there was an element of 'moral coercion' involved as far as persuading or 'socialising' their children into caring was concerned:

> *We would prefer not to burden them with*
> *our problems but in some cases or*
> *sometimes it is sort of moral blackmail,*
> *that you owe it to us, but I think that's*
> *not really the way to bring up children*
> *and you are really depriving them of their*
> *childhood.*
>   Mrs Mirza

Even though the parents thought, in theory, that children shouldn't have to care, not one of them wanted their children entirely replaced either by an informal or formal professional carer. It seemed that parents wanted their children to care, not least because they were so familiar to them. Furthermore, they seemed to feel they could trust their children more, and perhaps they also wanted their care because they could exercise control over their own children (even by persuading them to continue caring) where they couldn't over others. We have already seen that adult care receivers clearly found it difficult to establish a relationship of trust with a professional carer, but where their own children were concerned there was no such difficulty. Many of the parents also talked about the companionship they received from their children both as children *and* as carers:

> Well I know it's not right, they shouldn't
> have to look after me, but if they're happy
> that's all that matters. They'd sooner do
> it than outsiders. They are the best people
> to provide care because of love. We can
> have a laugh and a joke and that with
> children. We can't with outsiders.
>   Mrs Winterbottom

> Needless to say we all wish the children
> didn't have to care. I don't like asking her
> [daughter] to do it. We try and make it
> more light hearted. We're more friends
> than mother and daughter. I don't want
> her to get a full time job because she cares
> and it's company. Caring's not just
> physical, it's more than that, it's someone

> to laugh with, joke with - a carer and a
> companion.
>   Mrs Barker

In many respects it is perhaps not surprising that the parents didn't want anyone to replace their children as carers, or couldn't conceive of someone taking their place, as on the whole their children had always provided care, even if and when complemented by CCA or nursing support. In most cases the children were caring during times when professionals could not be there, especially during those crucial times such as at night (in many respects children are a 24 hour resource). Furthermore, considering the parents' perceptions of 'normality' - what parents kept referring to as 'normal family life' - having their children caring for them, as opposed to professionals, perhaps most resembled regular family life. However, some of the parents were aware of the 'caring contradiction' - of the conflict between their own caring wants and 'acceptable' levels of caring. Some of them had indeed confronted their own 'selfishness' in wanting to keep their children in the caring role, rather than have someone else take it on:

> I feel comfortable with her [daughter], but
> I'd like her to have more to herself you
> know. But I've never had anyone else to
> care, so I don't know who should be doing
> it. But I don't think they should really
> have to do it because they've got their life
> to live too haven't they?
>   Mrs Dunston

> In an ideal world I wouldn't be like this.

I don't know if I'd want anyone else caring because no one else has ever done it. No I wouldn't like her to be free of caring. She's done it for so long she wouldn't know what to do with her time if she was free of it.
  Mrs Barker

She [daughter] is preferable to outside care - better the devil you know than the devil you don't know! I'm probably a bit selfish that way I probably didn't want her to leave and I don't know what I'd have done if she had gone. Children shouldn't have to care. You do it for the love of it. You're there and it comes automatic.
  Mrs Walton

There clearly was a contradiction (and some confusion) over who parents felt *should* care and who they *wanted* to care, especially considering that none of the parents wanted their children to stop caring or be completely free of their caring responsibilities, (although some wanted their children to be able to have more freedom generally). This naturally conflicted with their feelings about their hopes for their children's future. Only Mr and Mrs Mirza had ambitions for their children to go on to University which might mean they should have to leave the caring environment.

Most parents said they wanted their children to be happy, not to suffer the same fate as themselves (i.e. with long term illness or disability) and to do whatever they wanted to do. However, interestingly, none of them expressed their hopes for their children's future in terms of leaving home in pursuit of

a career, or of being completely free from caring responsibilities. It is true that the children hadn't been able to express their personal or career ambitions very well in the initial study, mainly because caring had in effect limited their career opportunities (because of poor performance at school) and in many cases restricted their horizons, both in terms of their aspirations and in terms of their ability to think beyond 'tomorrow'. However, perhaps despite their better judgement, many parents seemed comfortable with the fact that their children had not expressed outright career plans:

She [daughter] never seemed to want to do anything you know. She never seemed to have any preference for a career at all.
  Mrs Dunston

I hope they do better than me. My eldest daughter is leaving home, but the one who cares for me now - no.
  Mrs Winterbottom

She's not leaving home, not getting married, not leaving.
  Mrs Barker

Conclusion

It is clear that the provision of care by children causes many anxieties for parents. They often have to struggle with their own guilt at having to participate in and be the recipients of their children's care provision and management. But perhaps more significantly parents must constantly confront the contradictions involved in child caring - between acceptable and unacceptable levels

of care provision and the reality of their own
child caring situation; between their own
practical wants and needs and the fact that, in
theory at least, they are aware that children
should not have to provide some forms of
care. Furthermore, despite these conflicts,
parents often engage in power plays with
their children as carers; they exercise control
over their children in order to maintain some
semblance of 'normal' family life, and because
they are all too often afraid of the conse-
quences of the loss of control over their
children, or the loss of control over their carer.

The Needs of Parents, The Needs of Children 4

In this chapter we look at needs in terms of the parents' requirements (we wanted to determine whether, as with the children, there was any recognisable pattern of need among adult care receivers) and we also examine what the parents perceived their children's needs to be, both as children *and* as carers. Finally we wish to ascertain the level of parental understanding in terms of the children's needs as expressed in the initial young carers study.

It was clear from the initial study that the specific needs of children as carers included their need for 'someone to talk to' as well as the need for information. The former was the only 'personal' need expressed by the children. Initially, when the topic was raised, the children only described needs in terms of what their parents needed most. It took some time before they recognised and talked openly about their own requirements.

Parental Need
It soon became clear that no pattern would emerge relating to the needs of the adult care receivers. Their requirements, as well as their personal stresses, varied enormously and were very much determined by individual circumstances and conditions. So, for example, practical needs among adult care receivers ranged widely from someone to lift the bed mattress, a need for a full assessment, to having the front door moved nearer the garage. Some needs, especially those culturally related, were very specific indeed and some of these would be problematic in terms of provision by either health or social services, as the following example illustrates:

In an ideal world we could afford to keep a servant or something like that. We could get a poor relative from Pakistan to come and live with us and we could provide them with food and clothing and some spending money, but in return they would obviously have to care for us, but the immigration rules are so tight that it's very difficult. We would also love a chapati making service.
  Mr Mirza

Interestingly, none of the parents highlighted a need for more professional intervention in the form of increased CCA or nursing support, although this was occasionally discussed as advantageous only in terms of relieving personal loneliness or the burden on the young carer:

I'd just like somebody to come in a bit more, let my daughter get out a bit more. When she goes out at night or anything I'd have to sit on my own here and you know I get a bit lonely and that.
  Mrs Dunston

What is interesting in considering the needs as expressed by the children in the initial study and those expressed by the adult care receivers here, is that the children openly talked of their parents' needs, but the parents talked of their own needs and not those of their children. The two sets of needs did not necessarily coincide. For example, not one of the adults expressed a need for a confidante or trusted professional to talk to, neither did they express a particular need for information. Even though the findings from

the initial study revealed a crucial need for some sort of resource and information pack for young carers *and their families*, it was clear from this study that parents did not appear to require such a pack for themselves, nor did they appear to perceive the usefulness of such a resource for their children. Indeed, when asked their thoughts and opinions on the type of information that should be included in such a pack, parents either didn't know or were ambiguous and said 'anything' or 'everything'.

Parents also did not appear to perceive a need for medical information, either for themselves or for their children, and this clearly wasn't because they (the parents) were, to steal a phrase, 'information rich'. Indeed, the level of awareness of benefits, support services or where to go for information seemed very poor. Furthermore, information about adult services appeared to be acquired on a very ad hoc basis, generally by word of mouth rather than via a more formal or recognised information source:

> *I can't remember at all. I don't remember who told me about the day centre...the DSS, no, was it the social services? What do you call that woman that goes round looking for what you wanted?*
> Mrs Dunston

> *Word of mouth really. My husband's second wife told us about mobility allowance.*
> Mrs Winterbottom

> *I was on two sticks before I went for mobility allowance. The person who told*

> *me about it was someone who got it but didn't appear to need it themselves and I was angry about that. It was through word of mouth really. No one tells you what you're entitled to.*
> Mrs Barker.

Interestingly, the level of awareness among the adults concerning their own medical conditions or disabilities was also surprisingly low, although it must be stressed, not as scant as the children's medical knowledge. Although it was clear that certain medical conditions, for example, multiple sclerosis, had taken a considerable time (sometimes years) to diagnose, and involved complex testing and consultations, the care receivers *still* seemed to lack any awareness of the full implications of their diagnosis. Some had made assumptions about their own conditions without seeking further professional consultation. For example, Mrs Barker said she thought MS was hereditary and she was convinced her daughter could get it. There seemed to be a general reluctance among the parents to seek out medical advice and support. Clearly if parents aren't accessing available medical advice, it is not surprising that the children, both as children and as carers, have little understanding about medical matters, since their only access to medical data appeared to be through their own parents.

The lack of understanding among parents in terms of the usefulness of an information (medical, benefits, support services etc.) resource, both for themselves and for their children, can perhaps be explained in several ways. Often the parents' own needs were so

diverse and uniquely individual that they had unrealistic expectations about information provision, thus many of the parents wanted immediate and appropriate access to help or advice (as Mr Mirza said: 'If there was one number you could just ring for advice about anything it would really help'). Furthermore, some of the adults had clearly had bad experiences of information provision, which had often been contrary and arbitrary - 'They tell you you can get something and then someone else tells you you can't' - Mrs Walton.

However, there did seem to be a general lack of awareness among the adults that their children might actually need to know about certain issues or aspects of caring - that they were in urgent need of information on several levels (as we outlined in the initial young carers research). In many respects the delivery of information *by* parents *to* their children was based purely on a 'need to know' basis, in that they didn't appear to tell them anything unless they asked, and if they asked then parents 'controlled' or regulated the level and amount of information provision (based as it was on their own very limited knowledge in the first instance). Certainly in terms of medical information, parents only seemed to tell their children/ carers so much and even then only if they were asked. In some cases this seemed to be because parents were wary of frightening or worrying their children about medical issues or indeed about the long term implications of caring:

I've told her that this [MS] is not going to kill me. It's bad enough coping with

things that are happening.
  Mrs Barker

She never asked about it [MS] or bothered about it.
  Mrs Dunston

She [daughter] was brought up with it [arthritis]. She didn't really understand it. She didn't ask about how it would progress. It was just day to day living. But she gets bits of pains in her legs now.
  Mrs Walton

So it is perhaps not surprising that parents failed to recognise the importance of an information resource for their children if they didn't willingly deliver information to their children themselves. However, it seemed that parents were generally unaware of their children's needs: for example, although 'someone to talk to' was identified as a priority requirement among the children, this was not perceived by parents as a crucial need for their children/carers. Indeed, as we have already mentioned there was a remarkable lack of awareness among the parents of any of their children's needs (both as children and as carers):

There's nothing I can think of they need. I just don't know. They never said that they want things.
  Mrs Winterbottom

It is not our intention here to suggest faults or major problems in the parent-child or care recipient-provider relationship. Indeed, any lack of awareness among parents

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regarding their children's needs may have more to do with the children's own silence than parental 'failings'. Furthermore, parents might not want to confront the idea of their children's anxieties and fears because they may be all too aware of their inability to allay them, especially if such anxieties relate to their caring tasks or circumstances.

Perhaps indeed the lack of perception of children's needs among parents is further evidence of the commitment and selflessness of children as carers - that despite their often difficult and painful circumstances, children still don't relate their fears or needs to their parents, or for that matter, to professionals.

Conclusion

In light of the fact that parents of young carers are clearly not in the best position to recognise, comprehend or manage their children's needs (considering the many burdens and stresses placed on both children as carers, as was evidenced from the initial young carers research, and parents as care receivers, evident from the findings of this study) it is not unrealistic to recommend or indeed expect professionals - care managers and planners - to support both children as the informal providers of care in the community and parents as the often reluctant recipients of their children's care. Many of the parents interviewed for this study suggested that responsibility for the provision of child carers' needs (including the need for information) must lie with those outside the immediate familial caring environment - those professionals who are *paid* to care:

Children need to be told they can ask for

help. They've got to be given the help until they realise they do need it. You've got to point out the positive side.
  Mrs Barker

Conclusions: Rights and Responsibilities

5

This study has examined the experiences of children who care *from their parents' perspective*. As such, it provides new insights into the nature of the caring relationship between parent and child carer, and also between paid professionals and parents.

Whilst the accounts of the parents largely reinforced the accounts of the children (presented in *Children who Care*) - especially in relation to the neglect by professionals paid to care - the parents' testimonies also give rise to a number of new issues and concerns. In particular they raise issues about the responsibilities of parents, and the responsibilities of paid professionals, towards children who care.

The Parents' Perspective

In this section we summarise the main findings of the study.

Why children care: Parents thought that their children cared for them because of their children's sense of affection or emotional commitment, not out of a sense of duty or pity. In our original study, however, the children had expressed their commitment to caring more in terms of 'no choice' or 'no alternative'. The parents did not see it in these terms.

Who should care/who parents wanted to care: All parents agreed that their children should not have to provide primary care, and yet at the same time the parents were dependent on their children for this care. The parents were able to distinguish between who *should* care for them (someone other than their children) and who they *wanted* to care for them (their children). Parents wanted their children to care for a variety of reasons, not least because

their children were so familiar to them; they felt they could trust their children more than 'outsiders'; and their children provided companionship; also having children caring from *within* the family as opposed to caring professionals from outside meant family circumstances more closely resembled regular ('normal') family life. In addition, parents were better able to control their children than outsiders.

Acceptable and unacceptable tasks: Parents had strong views about which tasks were acceptable and which were unacceptable for their children to perform. The line was drawn in relation to intimate and personal caring tasks. Parents felt that it was inappropriate for children to be performing intimate tasks for them, even if the children felt 'comfortable' with such roles. However, parents who had to rely on their children performing such intimate tasks felt less strongly about the line dividing acceptable from unacceptable. Even so, there were still some tasks which they considered 'no go areas' for their children. But while parents believed that, in theory, certain tasks were unacceptable for a child to perform, they also acknowledged that, in practice, these tasks sometimes *had* to be performed by their children.

Parental guilt and fear: Parents expressed considerable guilt and fear in receiving care from their children. These feelings were related to their notion of 'normal' family life. Parents were worried (but had to accept) that their children were not experiencing a 'normal' family life - for example parents accepted the restricted social activities of their children as a necessary, if unfortunate, consequence of caring. In addition, parents

did not want to keep their children home from school - most parents valued education highly - but in some instances it was inevitable that they had to keep their child off school, to care. Parents were aware that these circumstances rarely arose in 'normal' family households. They also feared being judged by others outside the family, and feared having the family split-up by professionals. Then there was a further, very painful fear - that their children may one day withdraw from caring.

Parental knowledge of their medical condition: The parents' knowledge of their own medical condition or disability was often superficial, sometimes uninformed. Generally, they did not understand the full implications of their medical diagnosis, for themselves or the implications for their children.

Needs: While children were able to talk of their parents' needs, the parents were far less able to recognise or articulate the specific needs that their children might have as carers. Parents seemed unaware of (or would not readily admit to) any problems or worries that their children might have regarding caring. They thought that their children coped well with their caring responsibilities. This may be further evidence of child carers' selflessness - that they didn't relate their fears or needs to their parents. When asked about their own needs, most parents said that they needed immediate and appropriate *access* to tangible, practical help or advice.

Information: The provision of information (through, for example, a resource and information pack) was not seen as an urgent need by the parents. Child carers, on the other hand, had identified information (on medical

conditions, money, advice agencies etc) as one of *their* main needs. There was a general lack of awareness among parents that their child carer might need to know about certain issues or aspects of caring. Parents also failed to recognise that their children might need information on several levels (practical information, counselling etc). Linked to the above, parents did not willingly deliver information to their children. For example, parents told their child carer about their medical condition *only* when specifically asked about it by the child.

Caring: a private family matter: Within families there was evidence from the parents' accounts that male partners would sometimes withdraw from caring and 'elect' a child into the caring role. Other family members, relatives and friends would often shy away from helping. The parent/care receiver was often reluctant to involve (adult) helpers from outside the family: they preferred instead to have their child provide their care. Caring was seen, and kept, as a private function within the family. Parents did recognise that caring helped to 'silence' their children - child carers rarely talked to others about the caring experience. Again, parents saw this in terms of the privacy of the situation and caring relationship - that it was important to keep these things 'within the family'.

Parental Control: Parents were involved in a number of forms of control over their children. These included prioritising their activities for them (for example, homework, watching TV, going out, etc), often without reference to what their children wanted. Parents would also speak *for* their children - asserting that their children 'didn't want to go

out', or had 'few friends to go out with'. This control may be related to parental fear that children may withdraw from caring if they are not properly controlled or guided.

Professional interventions: Parents were unwilling to discuss their children's caring roles with professionals and others outside the family. There was a genuine fear of what professionals might do - and whether the family might be split-up because of the child's caring role. In some of the instances where parents had kept their children home from school, for example, the evidence indicates a lack of flexibility among professionals and service providers (within education, but also in housing and social services) in dealing with the parents' predicament. The parents' accounts confirm our original concern that child carers are not recognised or identified adequately enough in schools and elsewhere, and that professional interventions - in their impact on young carers and their families - are often 'punishing', perhaps even abusive, in nature. Additionally, there was also evidence that where professionals *did* get involved in families, there were often tensions between parental and professional definitions of 'need'. At times parents expected a particular service to be provided to meet their need, whereas the professional had identified a different need. In Asian families there was a potential for this clash in perspective to be more pronounced. A successful relationship between the care receiver and professional seemed to depend on four factors: no conflict between the formal professional and the child; accordance over tasks - the client and the service provider must agree on what tasks need doing and which are priorities;

personality compatibility - a relationship of trust must be established; consistency and duration - the length of time the individual professional has provided caring assistance was very important in order for the client to become accustomed to them and their regular presence in the home. The parents confirmed that there were few networks *available to the children* to support them as child carers. The parents confirmed that formal paid professional support was directed at them as care receivers, rather than at their children as care providers. Parents believed that responsibility for providing for *their children's needs* must, however, lie with those professionals paid to care.

Discussion
The follow-up study provokes consideration of a number of important issues relating to the role and responsibilities of child carers' parents, and of professionals in contact with child carers and their families.

The Responsibilities of Parents
The study shows that many of the parents found it difficult to recognise or acknowledge that their children had specific needs as *child carers*. Parents were able to see that their children had needs (as children), and that these included guidance and control, but they found it almost impossible to refer to the children's needs as carers. So, for example, parents did *not* acknowledge that their child carers needed someone to talk to, or had information needs, whereas all the children in the original study had identified these two areas, and others, as important personal needs.

Additionally, most parents believed their children cared through love and affection: that their children wanted to care. Child carers, on the other hand, referred more to being elected and socialised into the role. For them, there was no choice but to care. (This is not to say that child carers didn't love their parents - they obviously did - and were committed to the caring role. But it is not a role that they would have chosen had they been given a choice).

Whilst parents did acknowledge that certain tasks were unacceptable for their children to perform, in practice this did not stop children performing them. In most instances there was no one else available or willing to do these tasks. So, despite parents acknowledging the unacceptable nature of certain child carers' tasks, the parents relied on the children to perform them - and they also said that they would not wish for anyone else to perform them. Child carers were entrapped by parental expectations.

The reluctance on the part of parents to identify the needs of their child carers, and their interpretations as to why their children cared and continued to care, can be related to a number of complex factors. Not least, as we have seen, most parents relied almost entirely on their children to provide care for them: this was a fact of life within these families. There was, in the true sense of the word, a *dependency* of parent on child. We have seen that, for many parents, this dependency is associated with fear, with guilt, or with silence. Certainly, parents shared their children's fears of becoming too well known by paid professionals, in case this led to the family being split up or separated (to protect

child, parent or both). But, as we have already mentioned, in many of the families this dependency was also associated with tight parental control of the children.

Parents exert control of their children in most families - this is an inherent and important part of family life and child development. Certainly, the parents in this study - like any parents - wanted to provide boundaries for their children's behaviour. However, there are at least three fundamental caring relationships going on within these families: a caring relationship between parent and child; a caring relationship between carer (child) and cared-for (parent); and a caring relationship between paid professionals, parents and children who care. The third relationship - involving professionals - is discussed in the next section. Here we want to make a few observations about the first two types of caring relationship, between parents/cared-for and children/carers.

The respective roles of parents (as parents and as care receivers), and of children (as children and as carers) create a complex matrix of rights and responsibilities. In our previous study (*Children who Care*) we identified a 'rights based' approach to working with child carers. The framework we suggested was based upon the understanding that children who care are both children *and* carers, and have rights as such. The child carers in our original study wanted to hold on to both of these worlds.

It is difficult to frame a set of guidelines or recommendations that rest comfortably between the contradictions and tensions inherent in being a child and a carer. However, as a starting point, we identified a

set of rights that could form the bedrock from which more detailed and specific guidelines, recommendations or approaches could be developed (these rights are reproduced in Appendix 1). These rights are tantamount to a statement of principle. Parents (and paid professionals) need to respect the rights of children who care.

But at the same time, children who care also have responsibilities towards their parents/care receivers, and towards themselves as developing children and individuals. We do not wish to focus on these responsibilities here; our aim is to highlight the responsibilities *of the parents* of children who care.

At times it was impossible to distinguish whether the control exerted by a parent on their child was in the child's interest *as a developing child*, or was *in the interest of the parent as a care recipient*. Some parents thought that if they did not exert strong control then they might lose their child carer - not because of professional intervention, but, effectively, through the child withdrawing from the caring relationship. Control in these families often appeared to have more to do with a complex power relationship between cared-for and carer, rather than the more 'typical' relationship that exists (with all its own confusions and contradictions) between parent and child.

Other profound issues are also raised that relate to the caring relationships between parent/cared-for and child/carer. One in particular is concerned with what parents can expect their children to do for them - the boundaries between acceptable and unacceptable tasks. Clearly such issues are

also embedded in the notion of children's rights and are tied up with the boundaries demarcating acceptable familial responsibility and accountability. The issues raise a number of critical questions. For example, at what age should it be acceptable for a person (child) to take *responsibility* for the care of their parent - for toileting them, for showering them or for dispensing medications? At what age should a child be *accountable* for this care? Will the age for responsibility and accountability depend on the 'ability' or 'maturity' of the child or - like the legal age for marriage, sexual relations, the vote - will it be fixed for all? Who will be accountable when a parent dies at home despite the best efforts of their child carer? At the moment we have no clear answers to these questions. And when we have the answers, we need the policy and guidance to develop responses.

It appears that parents are not in the best position to recognise, comprehend or manage their children's needs *as child carers*. This support needs to come from outside the family, from professionals across a range of agencies. Parents acknowledged that it must be professionals who take responsibility in providing for the needs of their children *as carers*. However, this is not to deny parents the key role and responsibility for their children's development *as children*. It is clear that parents were striving, with some difficulty and with considerable pain and anguish, to reconcile the contradictions between being a parent and being a care receiver. It was clear to them - they lived the experience every day - that their need *for* care relied on their children continuing *to* care. Parents attempted to provide as 'normal' a

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family life as possible given the circumstances (and this includes control). Parents need to be encouraged and assisted in this role by those professionals paid to care.

The Responsibilities of Professionals
The third caring relationship we identified was that between paid professionals, parents and children who care. The nature of this relationship is critical to the quality of life of parents and child carers. We have already suggested above some of the ways in which the relationship between paid professionals and parents may be more 'successful'. In addition, professionals need to be more aware of the problems involved in families where children are carers and where there is long term illness or disability present. There also needs to be agreement between the care receiver and the professional about the definition of 'need'; about *whose* needs should and can be met; and about *which* needs should and can be met. There also needs to be greater flexibility and sensitivity in the delivery of services, including a responsiveness to race, religion and culture.

The parents in the study identified a strategic role for professionals in contact with child carers and their families: professionals need to take responsibility, (and we would argue accountability as well) for identifying and responding to the needs of children who care. We believe that professionals need to:

• **Identify** child carers in their own work settings and environments, for example within schools, social services, health, etc.
• **Acknowledge** the contribution made by child carers, and their strengths and weaknesses.

• **Listen** to what child carers have to say about their experiences and about their needs.
• **Believe** the accounts of children who care.
• **Explain** to child carers the medical problems of parents, in ways which are commensurate with child carers' age and maturity.
• **Assess** the specific needs of child carers. Where children are the primary carers, this should automatically trigger a full assessment of their needs. These assessments ought to be conducted jointly by professionals concerned with community care and with children 'at risk'. This way, both the needs of child carers as children, and as carers, can be taken into account. It will be the responsibility of the professionals concerned to work towards reconciling the contradictions between the roles, and the service needs, of children who care.
• **Recognise** that child carers have needs which may be very different from - indeed can be in conflict with - the needs of their parents.
• **Consult** with child carers about the situations that effect their lives, about their caring roles, about their parents' illness, treatment and services etc.
• **Integrate** child carers into existing service provisions, including access to respite care, community care assistance, meals on wheels etc.
• **Develop** appropriate new resources and services for child carers which take full account of the racial, cultural and religious needs of child carers and their families, and which are sensitive to the educational, literacy and ability levels of children. These may include counselling and befriending schemes, respite care schemes specifically for child

carers, group work projects, etc.

• **Provide** child carers with the information they require to improve the quality of their lives.

• **Include** child carers' needs in future community care plans.

• **Remove** the fear from provision and support - the fear of isolation, uncertainty and punishment for caring.

• **Protect** child carers as children, and as carers.

• **Promote** the rights of children who care, as both children and as carers.

• **Enable** child carers to develop as individuals and as children by recognising and supporting them and giving them *a choice* - whether to continue caring, whether to accept services and outside support when appropriately offered, or whether to stop physically caring for their parent.

• **Advocate** for a 'better deal' for children who care: to assist them to attain their rights as child carers; to improve the quality of their life; to highlight their situation, experiences and needs to policy makers at national and local levels.

Different professions, and professionals, will have their own strength areas (and weaknesses) in the responsibilities that we have identified above. Some, for example, will be better at 'enabling', 'assessing' or 'advocating' than others - but all those professionals paid to care have responsibilities, and a key role to play. Professionals need to work across professional and organisational boundaries; they need to establish *which* profession must take *which* responsibility. This will also

require improved channels for inter-agency and inter-professional communication. Young carers have often fallen into the gaps between social services and education, and between health and social care. Agencies need to work together for children who care and their families, rather than against them. They must also be made more aware, be trained, sensitive and proactive - rather than just responding to crises as they arise. In particular, professionals must regard child carers as partners in caring.

There is also a key role to be played by professionals in supporting the parents of child carers. We have suggested above that parents need to be enabled to fulfil their own wishes to be 'good' parents - to provide a family environment that is conducive to the development of their children. Parents of child carers know that their family situations are 'different' from those found in many other families. Professionals must work in partnership with parents, and within the special circumstances of their family life, to provide the physical, emotional and intellectual environment for child carers to thrive as children. This is a key responsibility for professionals.

The critical questions for professionals now to address must be: how can the parents of child carers be enabled as parents? how can children be enabled to care, and be protected in their child and caring roles, without their family life being torn apart by heavy-handed child protection procedures?

The answers to these questions are to be found in the stories of parents and children who care.

Appendix 1

The Rights of Children who Care

'... It is difficult to frame a set of guidelines or recommendations that rest comfortably between the contradictions and tensions inherent in being a child *and* a carer. A starting point, however, is to identify a set of rights that can form the bedrock from which more detailed and specific guidelines, recommendations or approaches can be developed. These rights are tantamount to a statement of principle. We believe that young carers, as children and as carers have:

- the right to self-determination and choice (to be children, carers or both);
- the right to be recognised and treated separately from the care receiver;
- the right to be heard, listened to and believed;
- the right to privacy and respect;
- the right to play, recreation and leisure;
- the right to education;
- the right to health and social care services specific to their needs;
- the right to practical help and support, including respite care;
- the right to protection from physical and psychological harm (including the right to protection from injury caused by lifting etc.);
- the right to be consulted and be fully involved in discussions about decisions which affect their lives and the lives of their families;
- the right to information and advice on matters that concern them and their families (including benefits and services, medical information etc.);
- the right to access to trained individuals and agencies who can deliver information and advice with appropriate expertise, in confidence;

- the right to independent and confidential representation and advocacy, including befriending or 'buddying';
- the right to a full assessment of their needs, strengths and weaknesses, including full recognition of racial, cultural and religious needs;
- the right to appeal and complaints procedures that work;
- the right to stop caring...'

From: Jo Aldridge and Saul Becker, *Children who Care: Inside the World of Young Carers*, Loughborough University, 1993.

Appendix 2

Publications from the Young Carers Research Project

Publications presented in date order.

Aldridge, J. and Becker, S., *Children Who Care: Inside the World of Young Carers*, Department of Social Sciences, Loughborough University, March 1993.

Becker, S. and Aldridge, J., "The lost children", in *Community Care*, 18th March 1993, p. 23.

Aldridge, J. and Becker, S., "Children as carers", in *Archives of Disease in Childhood*, BMA Publishing, Vol. 69, pp. 459-462, 1993.

Aldridge, J. and Becker, S., "Excluding children who care", in *Benefits: A Journal of Social Security Research, Policy and Practice*, issue 7, April/May 1993, pp. 22-24.

Aldridge, J. and Becker, S., "Inside the world of young carers", in *CareLink*, (King's Fund Centre Journal), Spring 1993, No. 19, p. 3.

Aldridge, J. and Becker, S., "Children who care", in *Childright*, June 1993, No. 97, pp. 13-14.

Aldridge, J. and Becker, S., "Punishing children for caring: the hidden cost of young carers", in *Children and Society*, Vol. 7 No. 4, 1993, pp. 277-288.

Aldridge, J. and Becker, S., *My Child, My Carer: The Parents' Perspective*, Department of Social Sciences, Loughborough University, January 1994.

Aldridge, J. and Becker, S., "My child, my carer", in *Community Care*, 20th January 1994, forthcoming.

Aldridge, J. and Becker, S., "Children who care", in Family Policy Bulletin (Journal of the Family Policy Studies Centre), 1994, forthcoming.

Becker, S. and Aldridge, J., "The rights and wrongs of children who care", in Franklin, B., (ed), *Children's Rights: A Handbook of Comparative Policy and Practice*, Routledge, 1994, forthcoming.

Dearden, C. and Becker, S., *Resource and Information Pack for Young Carers*, Loughborough University/Nottingham Health Authority, July 1994, forthcoming.

Becker, S., (ed), *Children who Care in Europe: A Report to the Gulbenkian Foundation*, Department of Social Sciences, Loughborough University, August 1994, forthcoming.

children who care

- inside the world of young carers -

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Jo Aldridge and Saul Becker

When I think about all those years I cared for my dad, it makes me angry, not because I had to care for him - I wanted to care for him - but because I was left alone to cope with his illness for so long.

I wasn't just doing ordinary tasks like other kids might do around the house. I was having to cook for him, beg for money and food parcels so I could feed him, take him to the toilet, clean him up when he couldn't get to the toilet - because he couldn't get up the stairs towards the end.

No one should have to see their parents like that, when they lose all their bodily functions. I loved my dad and I couldn't bear to see him losing his dignity - getting more ill before my eyes. But because I loved him, I wanted to be with him. I wanted to look after him. I just wish someone could have helped me and that those who interfered in our lives and made them difficult could have left us alone...

Jimmy, aged 16

This is the story of young carers, children hidden from view, who provide the main 'care in the community' to their loved ones - parents and siblings - often with no help or support. It is an account of choice and responsibility turned upside down: of children having to perform the most basic, personal and intimate tasks, becoming their parent's parent; of professionals and organisations who are paid to care, but who simply look on, or look aside.

Through in-depth interviews with children in Nottingham, Jo Aldridge and Saul Becker take us inside the world of children who care. Using young carers' own words, the authors provide a critical commentary and analysis on the lost childhood of young carers, their fears and pain. But it is also about the strength and commitment that children show towards loved ones, often against all the odds. Aldridge and Becker's research, and the recommendations they make, cannot - indeed, must not - be ignored by anyone concerned to improve the position of children who care.

children who care ISBN 0 907274 01 3, @ 98 pp.

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my child, my carer
~ *the parents' perspective* ~
◆

Jo Aldridge and Saul Becker

"My daughter's washed me and dressed and toileted me. She's sort of just been brought up with it... it comes automatic. She seems to cope remarkably well... She's not leaving home, not getting married, not leaving at all... In an ideal world I wouldn't be like this. I don't know if I'd want anyone else caring because no one else has ever done it. No I wouldn't like her to be free of caring. She's done it for so long she wouldn't know what to do with her time if she was free of it."

Mrs Barker

"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... We've had a hell of a couple of years with adolescence and I haven't been able to cope with her very well... I'm very surprised that she hadn't turned before she did, but the thing is at her age she's turned on me... we've had a couple of years, it's been horrific."

Mrs Hunter

What must it be like for a parent to be cared for by their children - to have to watch your own child perform the most personal and intimate of tasks? In this companion volume to *Children Who Care: Inside the World of Young Carers*, Jo Aldridge and Saul Becker provide the parents' perspective on young carers' lifestyles and needs.

Returning to many of the families in their original study, and using the parents' own words, Aldridge and Becker provide a commentary and analysis of parents' experiences and concerns as recipients of their children's care. It is a story of fear and guilt, of parents painfully striving to bring up their children as best they can. It is also an account of the complex matrix of relationships, tensions and contradictions that exist between adult care receivers and child carers, between parents and children, and between parents, children and those professionals paid to care. The authors suggest that to understand and to respond to the needs of young carers and their parents we need to think in terms of rights and responsibilities: children who care have rights as children *and* as carers; parent care receivers have responsibilities for bringing up their children; professionals, paid to care, have responsibilities to work in partnership with both, to support parents as parents, and children as carers.