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# Young carers in Europe: an exploratory cross-national study in Britain, France, Sweden and Germany

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# Young Carers in Europe
# An Exploratory Cross-National Study in Britain, France, Sweden and Germany

Saul Becker (editor)

Jo Aldridge, Diarmuid Brittain, Jochen Clasen, Berthold Dietz, Arthur Gould, Linda Hantrais

Loughborough University
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Young Carers Research Group/
European Research Centre
Loughborough University

# List of Contributors

**ALDRIDGE, Jo.** Research Associate in the Young Carers Research Group, Department of Social Sciences, Loughborough University. Recent publications include *Children who Care: Inside the World of Young Carers,* (1993), *My Child, My Carer* (1994), *A Friend Indeed: The Case for Befriending Young Carers* (1994).

**BECKER, Dr Saul**, Director of the Young Carers Research Group, Loughborough University and Director of Studies for the Masters degree programme in Policy, Organisation and Change in Professional Care, also at Loughborough. Recent books include *Public Issues, Private Pain* (edited with S. MacPherson, 1988), *The New Poor Clients* (co-authored with R. Silburn, 1990), *Windows of Opportunity: Public Policy and the Poor* (1991), *Police Force, Police Service* (edited with M. Stephens, 1994).

**BRITTAIN, Diarmuid**. Doctoral Research Student, Department of European Studies, Loughborough University Recent publications include 'Les enfants soignants: Le cas de la Grande-Bretagne' ['Young carers: The case of Great Britain'], *Les Cahiers du CTNERHI* (1995).

**CLASEN, Dr Jochen.** Lecturer in Social Policy, Department of Social Sciences, Loughborough University. Recent books include *Social Policy in Germany* (edited with R. Freeman, 1994), and *Paying the Jobless: A Comparison of Unemployment Benefit Policies in Britain and Germany* (1994).

**DIETZ, Berthold**. Associate Researcher, Young Carers Research Group, based at the University of Giessen, Germany. Recent books include *Die Soziale Zukunft Europas [Social Europe? Conditions and Perspectives of European Social Integration]* (edited with J. Bardelmann and T. Schafer, 1994).

**GOULD, Arthur**. Senior Lecturer in Social Policy, Department of Social Sciences, Loughborough University. Recent books include *Conflict and Control in Welfare Policy* (1988), and *Capitalist Welfare Systems: A Comparison of Japan, Britain and Sweden* (1993).

**HANTRAIS, Professor Linda**. Professor of Modern European Languages, Department of European Studies, Loughborough University, and Director of the European Research Centre, also at Loughborough. Recent books include *Managing Professional and Family Life: A Comparative Study of British and French Women* (1990), and *Social Policy in the European Union* (1995).

# Forward

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 ... It's too late for me now. My dad died and I'm no longer a 'young carer', but for all those other kids out there who are in the same situation I was, then something should be done to help them. Not take them away from their mum or dad, but to help them care without worrying, without being frightened.

**Jimmy, aged 16, who cared for his dying father, Great Britain**

I had to push dad in his wheelchair in the street because mum was too embarrassed to do it. Neither of them know how I felt during that time ... I have told you [the researcher] a lot of things about my relationship with my father that neither he nor my mother know ... Caring for my father destroyed my teenage years. In that situation there is no such thing as respite.

**Sabine, now an adult, who cared for her father during childhood, France**

I tried and tried but it all became too much. Every time she would scream at me. In the end I gave up. I was able to say to myself that I wasn't obliged to support her. I don't have to have a mother. I don't have to suffer the guilt of having to be responsible for her.

**Monica, now 20, who cared for her mentally ill mother during childhood, Sweden**

I had to lift her, give her the medicine, take her to the toilet and so on. Later, when she was completely bed bound I received help from my mother. Both of us made the beds and showered her together. My mother was completely overworked at the time. She couldn't cope any more Granny was embarrassed in front of me. She was ashamed, for example, to be washed by me - but less so by my mother. Later however she did not even notice any longer who it was who washed her.

**Michaela, aged 15, who cared for her grandmother, Germany**

**Introduction**
**Saul Becker**

Young carers are children and young people under the age of 18 who provide care for a parent or relative in the community, usually within their own home. They can perform the most personal and intimate of tasks for their parents or other family members, often without any help or support from welfare agencies. Many children provide care at great personal expense -they are deprived of their childhood, many miss out on educational opportunities, few have established friendships or other support networks. No one is sure what the long term implications of caring are on a child's health or psycho-social development.

Many young carers are hidden. They are forgotten or ignored by policy makers and service providers at national and local levels; they do not feature in the literature on community care, family care and children's rights; and young carers' experiences and needs are not explicitly recognised in social and family policies.

Research conducted in Great Britain by the Young Carers Research Group has highlighted the experiences and lifestyles of young carers and their families in the City of Nottingham (Aldridge and Becker, 1993, 1994). The studies reported in this volume extend that programme of work to France, Sweden and Germany. The contributors to this volume all have expertise in social policy issues within at least one of the European Union (EU) countries under study. They have researched and published numerous articles and books on aspects of welfare in their respective country. Each was provided with expenses to conduct original fieldwork, following the approach and methodology established in the British young carers research. All the contributors have been concerned to examine the experiences and needs of young carers in their country, and the way in which welfare professionals and organisations view young carers and respond to their needs.

This is an exploratory investigation. It is the first time that the issue of young carer~ will have been addressed in some of the countries under study. Consequently, to conduct the fieldwork the researchers made contact with a number of statutory and voluntary welfare agencies in their respective country, with the intention of interviewing young carers, some ex-young carers, and welfare professionals and policy makers who had, or might have, an interest in the issue of young caring. In all, including the fieldwork in Great Britain, 19 young carers were interviewed, 8 ex-young carers were interviewed, 11 parents/care receivers and 67 welfare professionals/policy makers. All the interviews were conducted in the mother tongue, were recorded, and the tapes transcribed for analysis. A semi-structured interview schedule was used with the young carers and professionals, based on those used by Aldridge and Becker (1993). These schedules are reproduced as Appendices 1 and 2. Following chapters, although all the contributors worked to a common chapter structure.

It was critical for the researchers to have a working definition of 'young carer'. Because we wanted to be as broad as possible in this first exploratory study, we agreed on a number of

definitions that allowed us flexibility to include children caring in a number of diverse situations or circumstances. We started with a working definition derived from the Carers National Association (1992):

> A young carer is a child or young person under the age of 18 who provides the main (primary) care for a parent or relative in the community, usually within their own home, and most often without any help or support from welfare agencies/services.

However, we were conscious that in other EU countries this definition might not be readily understandable or accessible. Consequently, we added a number of other strands to the definition, in order to help EU contacts and professionals identify our research interests, and help them, and us, identify young carers who could be interviewed:

> A young carer is a child or young person under the age of 18 who lives in a one parent or two parent family where the parent(s) have a physical or mental disability, or where they have long term illness, or where there is drug or alcohol abuse/misuse (etc.), and the child helps to provide some of the main care for the parent(s).
>
> A young carer is a child or young person under the age of 18 who lives in a one parent or two parent family where a younger or older brother/sister has some physical or mental disability or illness, and the child helps to provide some of the main care for their sibling.

Rather than defining young carers by the level of their caring responsibilities and the absence of formal/professional support (which the first definition does), we defined, and identified, young carers by the impact on their lifestyles, experiences and childhood. Our hypothesis was that a child in a lone parent family or two parent family, who looked after a parent or sibling, could experience many of the effects cited by British young carers who had primary caring responsibilities, even though they might receive support or services from professionals or others, and even if they weren't providing the 'main' care. The impact, or restriction on their childhood, we believed, would depend on a number of complex and inter-related familial, social and policy-related factors, including the time spent caring, the level of responsibility, the intimacy or intensity of the tasks performed, the things 'lost' to the child, who shares the care or assists the child, the timing of care (when care is provided and how long it takes), the arrangements for the provision of welfare in the respective country, the legislation specifically concerning children and families, and so on.

**References**

Aldridge, J. and Becker, S. (1993) *Children ,Who Care: Inside the World of Young Carers,* Young Carers Research Group, Loughborough University.

Aldridge, J. and Becker, S. (1994) *My Child, My Carer: The Parents' Perspective,* Young Carers Research Group, Loughborough University.

Carers National Association (1992) *Young Carers Link,* March.

The four countries under study have different welfare regimes and represent different categories of family policy. However, they have all experienced a series of measures and changes in recent years, the purpose of which has been to enable chronically ill and physically or mentally disabled people to remain in their own homes. Whilst the long term implications of this shift are still not fully known (indeed, the process of community care or de-institutionalisation is on-going), research has shown that family, relatives and friends (especially women as mothers, wives or daughters) provide much of the care in the community.

The research reported in this volume reveals that, in many families across Europe, children also help to provide the main care in the community. These children are involved in a similar range of tasks and responsibilities, irrespective of the nature of the welfare provision within their country. A common impact amongst such children is the restriction on their childhood experience and development.

Chapter I provides the findings from the earlier British fieldwork, which has also been published in more depth elsewhere (Aldridge and Becker, 1993, 1994), and which acted as the 'model' for the studies in France, Sweden and Germany. Chapters 2 to 4 provide the results of the fieldwork conducted in these other countries. Each chapter also gives an overview of the relevant literature, and an outline of the structure of the welfare provision in that country. Chapter 5 brings together some of the main findings from the fieldwork in all four countries, identifies some of the key issues, and suggests an approach, utilising the UN Convention on the Rights of the Child, for putting young carers on to the international policy agenda.

What is now clear is the extent to which young carers have been ignored, even neglected, in the four countries under study. The initial reaction among policy makers, researchers, practitioners and the public in general, was to deny the existence of a problem. Little attention had been given to protecting children from the negative consequences of long term caring. This is the case in those countries with a tradition of explicit family policy, as well as those with a reputation for non intervention in the 'private lives' of families.

It is also clear that awareness raising strategies in all four countries will need to be developed if young carers are to be identified as a cause for concern, and for action. It will be interesting to observe over the next few years whether those countries with explicit family policies will

develop a more supportive, enabling framework for young carers. One can hypothesise that, after a country has become more aware of the existence and needs of young carers, then the type of welfare regime is likely to be of particular importance in determining the kind of response to, and support of, young carers in the community.

# Young Carers in Great Britain Saul Becker and Jo Aldridge

**A Literature of Omission**

Child caring in Britain, as elsewhere, is not a recent social phenomenon. Images of children who care can be traced through the novel, for example in the works of Dickens and Hardy. In Dickens' *Little Dorrit* (1857), the character takes on the role of 'little mother' and takes responsibility for her family at a very early age. By the time little Dorrit is 13 she is housekeeper and 'mother' to her brothers and sisters.

Images of the young carer can be traced back even further. In her work on children in history, for example, McLaughlin (1974) reports that at the beginning of the 11th century there is evidence that, due to the death of one or both parents, young children were cared and provided for by their older brothers or sisters. By the 13th century - when life expectancy was around 30 years of age - children who survived infancy were themselves more likely to be orphaned at an early age and forced into caring for other members of their family. Through the 14th to 16th centuries many orphaned children, from the age of seven, were often apprenticed or hired out as servants - to provide care in *other* families.

More recently, the writings of children's author Jamila Gavin have included stories of young carers, such as little Effie, who 'every day had to support the huge body of her invalid mother and help her from bed to wheelchair to bathroom to wheelchair, and finally, at the end of the day, back to bed again. Even the nights weren't her own... but Effie also had to see to her brother, Jackson and sister, Seraphina...'. Little Effie was, indeed, 'God's own child' (Gavin, 1991).

This commitment, often against all the odds, has also been portrayed by the British media as 'courageous'. As a reward for their bravery and selflessness, some young carers can expect to receive a golden heart from Esther Rantzen, or shake the hand of Princess Diana at the annual Red Cross Care in Crisis Awards. The British media has helped to construct the image of the young carer as a child of courage -God's own child.

Whilst novels, and media images, tell us something about the changing nature and experience of young carers in Great Britain, surprisingly little knowledge has been gained from academic research or official statistics. So, whilst there is considerable British research literature which focuses on the lives and needs of informal (unpaid) carers in the community, most of this fails to examine in any depth the particular experiences and needs of children who care (Fallon, 1990). The 1990 General Household Survey (GHS) of Carers indicates that there are about 6.8 million people in Great Britain who are looking after a sick, disabled, or elderly person (Office of Population Censuses and Surveys (OPCS), 1992). It is impossible, however, to derive from these data, or, for that matter, from any other official data sets, the characteristics

of young carers. However, through secondary analysis of 1985 GHS data, Parker (1992) has been able to determine that 17 per cent of carers aged 16-35 had responsibilities before their sixteenth birthday, and that a third of these had been assisting their parents. Parker comments:

> This means that of the 1.25 million carers aged 35 and under in 1985, some 212,000 had been providing care since before the age of 16 and, of those, around 68,000 for a parent (Parker, 1994, p. 9).

This is the only 'window' that provides an indication of the number of young carers in Great Britain. The OPCS (1994) has reported that it is not possible to interrogate the 1990 GHS data in any more depth, consequently, despite its limitations, this is the 'best' picture that is available.

Children who care have been excluded from official data collection procedures and analyses, and correspondingly, from the wider policy debates on community care and children's rights. So, for example, nowhere in the guidance to the National Health Service (NHS) and Community Care Act (finally implemented on 1 April 1993) are young carers specifically mentioned, despite the principle of the Act which is based upon listening to carers and providing for their needs.

**A Growing Awareness**

It is only more recently - from the late 1980s - that young carers have become more recognised and defined in Great Britain, and their experiences and roles have become more documented. As a consequence of a few small-scale pieces of work (see for example Page, 1988; O'Neill, 1988; Bilsborrow, 1992), and through the work of the Carers National Association (CNA, see for example, Meredith, 1991, 1992), there is now more open discussion and awareness of the needs of children who care. Young carers are themselves being given a voice, especially through the CNA. A number of conferences organised by the CNA and others have given young carers a platform to talk about their experiences, needs and rights (see for example CNA, 1993). Young carers in Britain are not asking for opportunities to receive golden hearts or shake hands with Royalty, but would prefer instead to be given recognition and support in their caring roles. This is not a message that some policy makers will want to hear: it is far simpler to give young carers tokens or awards, rather than find the resources or commitment to address their needs. It is far easier to talk about, and construct children who care as 'children of courage' or 'God's own children', rather than young carers with needs and rights.

**Young Carers in Britain: The Fieldwork**

We conducted our fieldwork in two phases. In 1992 we interviewed 11 young carers (aged 3-18) and 4 ex-young carers (who had been caring since early childhood), all from one large city, Nottingham. We also interviewed a number of welfare professionals in contact with

them. In the second phase, April-June 1993, we interviewed ten parents/care receivers of the Nottingham young carers, to build up a picture from the parents' perspective.

The very nature of young carers' lives means that, in practice, identifying and contacting them is problematic. However, with the help of a multi-disciplinary steering group (which consisted of welfare professionals from social services, education, health and the voluntary sector) we were able to locate and contact the 15 young carers and ex-young carers. A few of these were known directly to steering group members; most of them, however, were known to colleagues of the steering group or to other agencies/workers/religious leaders in contact with steering group members. These various organisations and individuals were contacted by the researchers in order to 'track-down' young carers.

Establishing both trust and the young carers' confidence was a considerable task, as many of the children were afraid and wary of outsiders intervening in their lives. Thus, it was necessary for the interviewer to engage in a process of reassurance and a period of establishing common ground and confidence when relating to the children. Once trust had been established communication became easier and many of the children spoke openly for the first time about their caring roles. Several hours were spent with each young carer in their home, where possible alone and away from the presence of others, including the care receiver, in order to avoid the children feeling restrained in talking about their caring roles and experiences.

We interviewed the children on two separate occasions. The first occasion involved the use of a semi-structured questionnaire. Young carers were encouraged to talk about their experiences across a number of themes, including their caring tasks and duties, their relationship with the care receiver, their aspirations for the future, their experiences of health and social services etc. All interviews were taped and the tapes later transcribed for analysis. The second session included a verbal questionnaire about the extent and nature of their caring responsibilities. However, although this technique provided some insight into the nature of their tasks, it is only through talking with children in detail, and listening to their stories, that we can gain understanding of their lives and relationships. Because the fieldwork in Great Britain was conducted some time before the fieldwork in France, Sweden and Germany, the interviews in these other countries followed the same thematic structure, and were able to utilise the experiences, and findings, of the British fieldwork to inform their research design and content. The findings of the British fieldwork have also been published elsewhere (Aldridge and Becker, 1993a, 1994a). The account and discussion below draws on these publications.

## The Young Carers' Perspective

### *The Roles and Tasks of Young Carers in Britain*

Our findings show that children are undertaking major responsibilities when they are caring for their parent/relative in the home. They are, in effect, taking on many parent-type roles. Indeed, not only did we find evidence of, for example, children as young as three years old providing feeding assistance for a grandparent, but also children carrying out a wide range of tasks from basic domestic duties to very intimate personal tasks such as dressing, showering and toileting parents as well as cleaning them up when they became incontinent. The young carers told us about the tasks that they had to perform:

> Well she's got a catheter in so I just have to empty the bag.
>
> I'm sort of lazy really, I've got to say it. I help her to the toilet, shower her, stuff like that.
>
> To help my dad out I dress him, take him to the toilet, keep him warm, listen for him in the night, give him medicines, watch him because when he smokes he drops his fags on the floor, he might set light to himself.
>
> I would get up, get a wash, put the kettle on, get a bowl of water, sponge, soap, give my mum a wash, get her dressed, go and get something from the shop for her, brush her hair and teeth.
>
> From the age of nine I was doing all the dinners and everything - I shouldn't have been doing all that.
>
> I used to hate seeing her naked. I hadn't seen an older woman like that. I know it's my mother, but it's just something you don't do, you don't see your mother naked.
>
> It's horrible having to do that sort of thing for your dad. It's degrading and it was especially degrading for my dad losing control of himself, and then having to be washed and cleaned up by me.

Questions of the long-term effects of such duties on children's psychological and psycho-social development have yet to be fully explored. Certainly, there are clear dangers when children are having to perform tasks which threaten their own physical well being, for example, more than half of the young carers interviewed in the study were assisting with their parents' mobility, including lifting them upstairs or onto the toilet, and for some children this had caused physical injury or exacerbated existing injuries or strains.

### *The Violence of Young Caring*

For children, the onset of caring in the home is often violent and unexpected. Many of the children interviewed were at one time living a relatively constant secure existence, being the recipients of parental love and care, with responsibility for their lives and well-being resting in hands of their parents. However, all to often the onset of caring was not gradual (although

the later extension of responsibility may be); often it coincided with the sudden absence or death of one parent and/or the onset of illness of the other.

Although initially a child may not have to undertake, for example, intimate caring responsibilities such as toileting, because the parental condition may not require it, they may have to perform such tasks eventually as the condition progresses is important to stress that the nature and extent of caring responsibilities among children is very much determined by the nature of the parental condition). For example, one young carer's mother was diagnosed as having multiple sclerosis soon after the sudden death of the child's father. The unexpected change in her family circumstances, the sudden onset of caring responsibilities, coupled with the grief over the loss of her father had a violent impact on the child. For her and for many other young carers thrust into such a role this can seem like a punishment. Indeed many of the young carers in the study, when talking about the onset of care, talked about it in terms of a punishment o something they had unwittingly do wrong. This is a theme we return to in more detail later in the chapter.

On occasions, children who care can also be the victims of physical violence from the parent care/receiver, especially when considering the nature of the parental condition or illness. For example, one young carer in the study was caring alone for mother who had Huntington's Disease one of the symptoms of which is unpredictable often violent behaviour.

Eventually she had elected to be separated from her mother because her violent outbursts had become so intense. Another young carer had been the victim of his father's uncontrollable violence during fit which was caused by his father's incureable brain tumour. For these children this too seemed like a punishment (and from the very person they were offering their love, care and attention), despite the fact that in such cases the violence was an intentional act of malice, but was the symptom of a medical condition.

***The Effects of Caring on Children***

The effects of caring on a child can be manifold and complex. This is certainly the case where the nature and extent of caring responsibilities are intense, in the circumstances where the young carer is the sole provider of care; and where there are no other adults in the home apart from the care receiver; and where the care receiver's condition is such that it require constant attention. The children spoke I us about the effects:

> I didn't used to talk about it. I didn't want anybody knowing our business still don't, but I've grown up a lot, I' had to. You've got to.

> I went out a couple of times once and stayed out a bit later than I normally did, come home and she's messed herself. I came in a happy mood, had a few drinks with my friends and then I've got to start stripping the beds and things like that... then I felt guilty when I realised one day what I was doing. I thought I shouldn't go out so much.

> The teacher asked me who did the cleaning up in the house and I said that I did it and she asked me if I wanted to have some of my classmates to come round and help me clean up. I said no thank you. Then she bought my mother a plant. She got the class to club together and bought my mother a plant!
>
> Dad will be really ill sometimes and sometimes I'll get pissed off about that. You just get so racked off...you just drop off to sleep and suddenly you hear him shouting for you. You never get two minutes on your own in this house, sometimes you think, 'Oh I've got to get some time by myself' and walk out, but I always come back.

Caring can severely restrict children's lives. It can have implications for their physical and psycho-social development as well as their educational prospects. Many young carers are forced to lift and carry their parents up stairs and from one room to another. This can often cause injury to the child (or indeed the parent) or exacerbate existing ones. Friendships and social activities are also severely restricted when children undertake primary caring responsibilities. They often have to forgo socialising, and friendship networks can suffer as a result. Caring can also place a 'silent curfew' on children so that when they do go out, they often have to return early to carry out their duties, or the care receiver can put pressure on children to return early to the family home.

Many young carers are persistently late or absent from school. Their educational performance can be severely restricted. Their aspirations for the future are often very narrowly defined, if defined at all (Aldridge and Becker, 1993b).

**The Parents' Perspective**

In the second phase of our fieldwork we returned to ten of the families in Nottingham to interview the parents (Aldridge and Becker, 1994a; Becker and Aldridge, 1994b). These parents were largely dependent on their children for their physical and, in many respects, psychological well being. The parents' statements often provide a picture of fear and guilt, and of parents striving to bring up their children as best they can. One parent, Mrs Mirza, commented:

> 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 to perhaps reciprocate.

Another parent, Mrs Hunter, commented:

> 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.

Like Mrs Mirza and Mrs Hunter quoted above, Mrs Barker is cared for by her child. Mrs Barker has multiple sclerosis. Her daughter, Diane, has cared alone for her since the age of eight. Diane, now aged 17, has no choice but to undertake the caring role and her mother has no choice but to accept care from her. There is no alternative. Both Diane and her mother are caught in a caring trap. Mrs Barker commented:

> 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.

As care receivers, parents recognised that although professional care was available to them as ill or disabled people, no one supported, or indeed recognised, the specific needs of their children as care providers. As Mrs Winterbottom commented:

> 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.

or Mrs Barker:

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

Parents shared their children's worries about the possible consequences of professional interventions. Professionals posed a threat to family and caring life. Parents recognised that they and their child-carer needed support, but were afraid that the consequences of asking for outside help might mean the loss of their child, their carer. Mrs Barker again:

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

***Parental Control***

Most parents considered that their children managed their care reasonably well. While they recognised their children were neglected by outside caring agencies (and indeed by neighbours, friends and even other family members) parents were unaware of many of the problems and needs that their children faced in relation to caring. This is related to the silence imposed on children by the caring experience, a silence which often extends to their parents. Children didn't want to burden their parents with their caring anxieties or stresses, and parents wanted to keep the caring experience within the private domain of the family.

Even though, in terms of their domestic and physical circumstances, parents were relatively powerless, they still exercised strong control over their children, their carers. Parents controlled their children's lives by prioritising their duties, their social activities and their school work. 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. Controlling their children/carers in such a fashion appeared, for many parents, to be a form of ensuring that their children continued in their caring role. Furthermore, such control procedures seemed to comfort parents that they were providing as close to 'normal', or regular family life as possible. Control 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.

***Acceptable or Not Acceptable?***

In families where a child is the main provider of care, many complex practical and psychological issues emerge. The rights and wrongs of child caring predominate. Parents had strong views about which tasks are acceptable and which are not acceptable for their children to perform. In every case parents agreed that personal or intimate 'nursing' tasks such as toileting and bathing were unacceptable duties for their children, causing pain and embarrassment for both parent and child.

Although all parents agreed that it was unacceptable in theory for their children to perform these and other intimate tasks, the reality was that there was no alternative. In practice these tasks had to be performed by children. Mrs Mirza commented:

> Personal tasks such as bathing and toileting would be totally unacceptable to us, because that's not really children's work. I mean children would obviously do it because again they would feel a moral obligation to do it but I don't think that's a job for children.

Or Mrs Barker:

> 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.

Although being forced to accept care from their children was distressing for parents, identifying suitable alternatives remained problematic. Many parents did not want their children to cease caring (and indeed many of the young carers said they did not want to relinquish their caring duties entirely) but equally parents did not know how to reconcile the contradictions between caring and childhood, between who they wanted to care (their child) and who should provide care. Most parents thought that professionals from outside the family should provide for their intimate care needs, and these professionals should also support their children as young carers. But, as we have seen, there was also fear of what professionals might do.

## Punishing Children for Caring

Although many key medical, health, social services and education professionals may be involved in families where there is a long term illness or disability, they are not necessarily identifying carers where these carers are children. Indeed, where identification generally has taken place, subsequent interventions have very often been punitive in nature (Aldridge and Becker, 1993c). Social workers and education welfare officers have threatened to pursue legal proceedings for non school attendance or because the child is considered to be at risk; community care assistance (home help) has been withdrawn from families because a young child is considered to be 'old enough' to cope; general practitioners have ignored young carers when considering the medical care and treatment of their patients; other professionals, whilst in contact with the 'care receiver' have failed to engage with the needs of young carers, assuming that what is good for the parent is also good for the child who cares.

To be punished for caring is hard to comprehend when you are a child. And the messages that this gives children during a critical stage in their psycho-social development may influence the way they perceive, and value, caring and family responsibility in adult life. But punishment does not just come from professionals. Family and friends also punish young carers.

### *Punished by Family and Friends*

In some cases we found that another adult in the home or even another parent and/or sibling exacerbated the young carer 's feelings of being punished by failing to support them, failing to take on caring duties themselves and by directly electing them into the caring role. We

found, for example, that where there were two parents in the home, the able or well parent often refused to care for their spouse and expected the child to compensate for their own (the able parent) caring inadequacies by undertaking primary caring responsibilities. In such a situation the least powerful member of the household (the child) is being punished by the most powerful (the able parent). For example, one young carer in the study who cared for her mother with multiple sclerosis provided the primary care (including dressing and bathing) even though the father was physically capable of caring. However, he refused to partake in any caring duties and elected his daughter as sole carer. As she pointed out:

> He finds it hard to face, I know because he once said he had lost a wife, he hadn't got a wife who could stand beside him in the pub. He sees other men out with their wives, but he wouldn't dream of taking her out in the wheelchair.

Sisters and brothers can also perpetuate this experience of punishment by avoiding caring duties or by being persistently unavailable for caring tasks. Friends too are not excluded from this process. Often young carers' social lives and friendships are severely restricted by the caring process not only because of the pressures of caring - restrictions such as not being able to stay out long, increased caring tasks if they do go out, or simply because young carers often have to provide virtually 24 hour attention - but also because friends, even close friends, do not understand the pressures on children who care or are too young to comprehend the implications of caring and are unable to deal with it sensitively.

***Punished by the Caring Professions***

Although services are targeted at adult carers, including respite care, support groups, and care attendant schemes (see Twigg, Atkin and Perring, 1990), currently there are very few services aimed at meeting the needs of children who care.

The notion of punishment for caring is carried over into the professional field -those who could be potential supporters and advocates for children in the caring role. However, our findings revealed that, at no time or point of intervention in the children's families, were welfare professionals either talking to children about their caring roles or identifying and responding to them as the providers of care.

A child may see a community nurse or community care assistant in their home regularly to provide for the welfare and needs of their parent/s. but have no contact whatsoever with them in terms of their own needs or their own responsibilities as care providers. However, it was clear from our findings that such professionals were aware that children were undertaking caring responsibilities, but chose to overlook, or not engage with this fact. This could in the main part be due to an inability on the part of these professionals to deal effectively with young carers and provide for their needs, and also a tendency to focus entirely on the needs of the care recipient and not extend the boundaries of their professional interest to the children in the home (see also Dearden, Becker and Aldridge, 1994a). Much of the literature on

informal care emphasises that the needs of carers and the needs of service users can be at odds. This conflict may be particularly acute where the carer is a child looking after their parent.

We found evidence that nurses and community care assistants were aware that children, for example, were lifting their parent up and down stairs or onto the toilet, and yet allowed such a situation to continue. This could be because professionals feel unable or unsure of how to deal with such situations. Certainly some professionals had been reluctant to train children in lifting techniques, perhaps understandably as this could be considered to be condoning lifting, and there are dangers to children when undertaking such physical tasks. However, all too often the reality is that children are offered no alternative and are thus left little choice but to continue lifting their parents without any form of support or advice. Two of the young carers interviewed who were lifting their parents regularly had been promised to be shown how to lift 'properly', but such training had not been forthcoming and they had given up waiting for advice.

Although we found that professionals were neglecting young carers in their field of interest, community care assistants (CCAs) in particular were acknowledging children's abilities as carers by *withdrawing* services. For example, although support and advice or advocacy had not been offered to young carers by such professionals, some CCAs had suggested that the provision of care for the care receiver was no longer necessary once the child reached a 'suitable' age to provide care themselves. However, the criteria of what constituted a suitable age varied from 12 to 16, revealing a lack of consistency and resulting in uncertainty and confusion for the children themselves. Here again we can see how the young carers may believe themselves to be the subject of indirect punishment, in that outside support may be arbitrarily withdrawn leaving them inexplicably to cope alone, when they, for example, reach their 12th birthday. This is particularly interesting considering that many adult carers have access to CCA and nursing support for the care receiver, regardless of their age or indeed their ability to care.

However, it was evident from our findings, and has been highlighted elsewhere (Alderson, 1992), that adults enjoy greater autonomy and access to services and as carers enjoy a greater level of communication with professionals, perhaps on the one hand because of the removal of fear (the fear of being separated from their loved ones no longer exists) and on the other, they are in a much more powerful position to request services. As Alderson (1992, p. 163) points out, children are the least powerful social group. Yet, as carers, children are obliquely accredited competence to deal with adult responsibility but are denied the fundamental right of being listened to and of being involved in decisions which affect their lives. A role is conferred on them, a choice denied them and yet they are considered sufficiently mature to deal with the rigours and pressures of intimate caring.

Although we found some young carers who had access to social work support (indeed these professionals were the only ones directly involved in the children's lives and whose attentions

were not aimed exclusively at the care receiver) we found that such support had been instigated by other problems, for example through persistent non-school attendance or reports of violence in the home (as was the case with the young carer whose mother had Huntington's Disease). Furthermore, at no point did any of the social workers involved in the children's lives engage them in conversation about their caring responsibilities or their needs as young carers.

However, it became clear from talking with the children that social workers were regarded with uncertainty and suspicion and were never adopted as advocates whom they could take into their confidence. This seemed to be based both on experience and expectation, some of the young carers had bad relationships with their social workers and some associated their presence in their lives with the threat of separation from their families. This latter point was also caught up once again with the notion of punishment, that the children would be taken into care, or the care receiver institutionalised, as a punishment to the child for their inability to cope with caring responsibilities. As Meredith suggests, this response is unfortunately all too common:

> At present people often fear that a social worker's response will be to put their child into care and sadly it is apparent that the option of care proceedings is used, or threatened, much too early (1991, p. 9).

Nor did we find any evidence of young carers who had successfully consulted their family GP for their own needs and requirements in terms of their caring roles and responsibilities, or for the strains associated with caring. Some of those interviewed had tried to talk to their doctors, but found constraints of time and a tendency to treat the symptom rather than the cause meant that they were discouraged from regarding their doctors as helpers. For example, one young carer wanted to talk to his doctor about care management and how to deal with his brother's (for whom he cared) unpredictable behaviour, but was soon discouraged because he could only see his doctor 'for one or two minutes'. Another young carer had gone to her doctor in desperation, feeling unable to cope with the strain of caring for her mother, but was simply prescribed tranquillisers.

Twigg suggests (1992, p. 70) that although GPs are ideally placed to recognise the needs of carers (as the majority of the population contact a doctor at some time) this is not necessarily the case due to the constraints of practice time and the inability of GPs to pick up on social issues. Twigg suggests that carers need to be very assertive and confident to shift attention to their needs, but clearly when the carers are children this ability is undermined further.

The most overt form of punishment for caring appeared to be in school. Most of the children interviewed had been consistently late or had missed considerable amounts of school (sometimes years) because of their caring responsibilities at home. One of the children, aged 15, was unable to read or write. Although it was clear from interviewing the children that

they were reluctant to talk to teachers or school staff about their home conditions, the same staff were not picking up on stresses and strains in young carers.

Indeed, the most common form of identification of a young carer's circumstances was when their parents were expected to attend parents' evening, and could not attend because of their illness or disability.

Furthermore, if a young carer 's lateness or absences were noted by teachers, more often than not they confronted the child in front of their classmates and forced them to explain. This often led to embarrassment and distress for the young carer. Again, we can see how young carers could interpret this response as punishment for a commitment they had made to their parents. Young carers' lives were not as simple as getting up in a morning, eating breakfast and getting to school, on time. As one young carer explained:

> I wasn't like every other kid, I didn't just have to get up and just eat my cornflakes and then go to school... I was shouting [at the teacher] and saying 'I'm trying to get by as best I can and without your support how am I supposed to get on well in school?' She turned round and said 'Oh well then we'll let this one pass by'.

Unfortunately, this seemed to be a common response from school staff, they either ignored the problem or in some cases did not believe the child even after confrontation. Following long term absences (four of the young carers interviewed had experienced serious problems at school or had taken long absences) the school authorities did intervene, but in a manner which was directly disciplinary, involving prosecution or care proceedings. For example, one of the young carers had missed two years of school in order to look after his father who was dying from a brain tumour. Initially the school authorities prosecuted the father, and then they threatened to place the child in care if he did not attend. Eventually the father died and such action was never taken. Here again we can witness the professional response to treat the symptom rather than the cause, and that children are effectively punished - if not abused - for their commitment to the caring role. We use the word 'abused' here because, to a large extent, community care in these families is effectively care by children, and children bear the costs of this role in terms of their childhood, development and personal security.

Our findings revealed that the only source of comfort and self worth available to the young carers came from the caring process itself. It seemed that only in the relationship between the carer and the cared-for was any form of gratitude, appreciation and love expressed. It did not seem surprising therefore that the young carers maintained their commitment to their parent/s despite the continual strain and threat of punishment from outside the caring environment. In a situation where a child is caring for a parent the traditional role of parent/child has, to some extent, been turned on its head. However, it was clearly still very important for the young carers to identify with the parent as a figure of respect and affection, despite the fact that

responsibility for parental welfare now lay considerably in the hands of the child. Parents also wanted, indeed needed, to maintain their own authority as parents.

**Legislative Forces**

The problematic position of young carers also arises from contradictory pressures contained within current British welfare legislation and philosophy concerned with children and community care. The Children Act 1989 (DoH, 1991) defines and clarifies the rights of children - and implies a notion of childhood that is safe and protected. Section 17 of Part III of the Children Act states:

> It shall be the duty of every local authority (a) to safeguard and promote the welfare of children within their area who are in need; and (b) so far as is consistent with that duty, to promote the upbringing of such children by their families, by providing a range and level of services appropriate to those children's needs.

For the purposes of Part III a child shall be taken to be in need if:

> (a) he is unlikely to achieve or maintain, or have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority, or (b) his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services (Section 17(10)).

Young caring imposes real strains on this view of childhood - on their rights and needs as children - because where children are carers, they are essentially providing care and security for their dependant, often at the expense of their own childhood, welfare and needs.

The community care legislation (DoH, 1989, 1990) promotes a different tension By encouraging people to stay in the community for as long as possible, and by enabling and facilitating the development of networks for community care, there is key role envisaged for informal care (indeed the White Paper acknowledges that informal carers will continue to be main providers of care). So, one strand legislation is establishing a framework I community care and support of carers, while another strand attempts to protect children and establish their rights. There is a tension between the two when children are carers.

A critical question to be addressed here should young carers be viewed and tree ed as children of courage - 'God's own children' - or children in need? The neglect and punishment of young carers by professionals, and the absence of a clearly defined policy agenda for young carers, partly arise from the difficulties inherent in answering this question; an from the problems of 'classifying' young carers' experiences and needs. For the British media the answer is far simpler the child carer is a child of courage to be applauded and

rewarded with some symbol, token or appreciation. The media has generally failed to penetrate and engage with the contradictions of the child caring experience but at the policy level especially given thee growing evidence about lifestyles and need, the 'God's own children' approach is hard to sustain. Local social services departments, charged with statutory responsibility for community care and child care, have been unsure as to whether young carers fall into the policy and practice domain of child care or adult and community care. This is despite, or even because of, the Children Act and community care legislation. The 'boundary' dispute has led to the needs children who care going largely unidentified has led to the needs of children in the local resource allocation and planning process. At national level too, despite the advances made by CNA and Crossroads Care, and the publication of recent research findings, young carers a rarely mentioned in Department of Health reports on community and informal care or in the discourse on children in need,. for that matter, in the literature of the children's rights movement more generally. To a large extent, therefore, young carer remain obscured from the various policy making arenas. When they are recognized they are constructed, especially by the media, as brave and courageous, or, more recently, as victims.

An answer to the complex question on the status of young carers is perhaps closer now that the United Nations Convention on the Rights of the Child has finally co~ into force in the UK. The Convention views children as especially vulnerable, with a right to expect special care, assistance, and protection, and a right to be heard and respected. In the UK's first report to the UN Committee on the Rights of the Child, the British Government stressed that:

> There is an increasing understanding in the UK of the importance of providing children with a good start in life and ensuring that their material and emotional needs are met. It is our aim that every child should be able to enjoy a secure and happy childhood. Such a childhood has a value of its own but it also provides the best preparation for adult life and for empowering children to participate fully in society ... The Government is conscious of the need always to be vigilant to identify areas where there are deficiencies in our arrangements for children and to take steps to tackle them (HMSO, 1994, paras. i & x).

Quite clearly, current arrangements for young carers fail to ensure that they have a secure childhood. The Children's Rights Development Unit, established to independently monitor the Government's compliance with the Convention, was quick to identify the shortcomings in policy for young carers. It states: 'Given the circumstances of many young carers and the restrictions placed on their potential health and development, it would seem appropriate to define them as "in need" (CRDU, 1994, para. 5.4.8).

Recent qualitative research, including our own, has attempted to give a voice to children who care, to provide young carers with the opportunity to construct their own image, to define their own needs and to enable them to tell their own stories. This is in part both the method, and epistemology of qualitative research: to embrace the insider view, to report from the perspective of those studied, to be concerned with process rather than merely social structure

(Bryman, 1988). When given that opportunity to speak, to be reported and to be heard, young carers see themselves as key providers of care as well as children with special needs. Many young carers want to be listened to as children *and* as carers. The development of services for young carers, and a policy agenda, will need to take account of this essential duality in their function, experience and needs.

It will also have to take account of the need to protect young carers, and their loved-ones, from themselves and from each other. The impact areas of caring on children have much in common with the impact of other forms of child abuse and neglect: low personal esteem, lost childhood, growing up before time, insecurity and instability within family life, impaired psycho-social development, poor educational achievement, silence and secrets, few friendships, few opportunities. Young carers often experience tight parental control from the person they care for. Additionally, the parents of young carers often fail to recognise that their child -their carer - has specific needs as a carer, as well as a child (Aldridge and Becker, 1994a).

## A Rights Based Approach

### *The Rights of Young Carers*

A World Health Organisation study (1982) identified four categories of need in relation to children's development: the need for love and security; the need for new experience; praise and recognition; and the need gradually to extend their responsibilities in the family environment. The research reported above reveals that most, if not all of these needs are often undermined by the caring experience.

The gradual extension of responsibilities among children bears little relation to the actual experience of most children who care. The WHO study suggested that such responsibilities should start with very simple personal routines. Young carers' routines on the other hand were often of a very demanding and intimate nature. Their introduction to adulthood (whilst still a young child), and to caring, was often unexpected and sometimes violent. Most young carers appear to have little choice in taking on their caring tasks. They are often 'elected' into caring responsibilities and then socialised into the role (Aldridge and Becker, 1993a).

The challenge ahead is to 'ensure the opportunity for optimal flowering of each individual's autonomy' (Doyal and Gough, 1991, p. 207). Young carers need to be given the recognition, opportunity and support to flower as individuals, as children and as carers. Guidelines or approaches for action, therefore, need to be based upon young carers' own statements of need, upon their own construction of child caring. It is important that adults, and professionals in particular, do not impose their own (adult) ideals concerning young carers' best interests. A starting point when considering the way forward is to acknowledge the

unique situation of each young carer; so that any assessment of their needs is made on an individual basis. What is right for one young carer might not be right for another.

Furthermore, any guidelines for service delivery must inevitably be based on philosophical and pragmatic principles. These include the recognition and observation of children's rights, practical policy recommendations based upon these rights and pragmatic considerations in relation to professional intervention and service arrangements. Alderson (1992, p. 156) has suggested that 're-thinking childhood in terms of rights opens the way for children to be consulted more fully in defining their interests'.

In the remainder of this chapter we outline some of the general principles that might serve to guide the development of specific responses and services to young carers in Britain, and elsewhere. The framework we suggest is based upon the understanding that children who care are both children and carers, and have rights as such. We wholly accept, indeed much of this chapter has highlighted, the tensions inherent in being a child and a carer at the same time. Nonetheless, the young carers in our studies wanted to hold on to both of these worlds. What they wanted from others, including professionals, was for their contribution to be acknowledged, recognised and valued, and for some help in the performance of daily routine chores and intimate personal tasks. No young carer was asking to be 'taken away' from the caring role, nor were they asking for their loved-one to be taken away. What they were asking for was someone to talk to (who would listen and understand) and for a little help now and then.

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 physically caring.

**Responding to Needs and Developing Services for Young Carers in Britain**

Moving beyond this statement of rights, to considering more specific service provision and professional interventions, requires us to consider a number of other factors and issues. However, a general 'test' for any service development or provision will be the extent to which it measures up against - indeed promotes - the set of rights identified above.

Young carers' lives, both as carers and as children, are fraught with anxiety, stress and uncertainty. As a consequence of the time they have to give to caring, their living conditions are often painful and distressing and their futures bleak. Young carers need to be given the recognition, opportunity and support to develop as individuals and as children, but they must also be able to make their own decisions about caring - whether to continue caring, whether to accept services and outside support when appropriately offered, or whether to stop physically caring for their parent.

Clearly such issues are embedded in the notion of children's rights and are tied up with the boundaries demarcating acceptable familial responsibility and accountability. Any guidelines or approaches for action should be based on the clear expression of those rights and young carers' own constructions of need. These needs - especially for services - are modest. All the young carers in our studies said that what they needed most was 'someone to talk to', someone who would befriend them, understand their circumstances, empathise and represent them without further threat of a 'cascade of intervention' or separation from their families. The fear must be removed from provision and support - the fear of isolation, uncertainty and punishment.

Young carers also said they needed information and advice. At present, many are not receiving the information which is crucial to their day-to-day quality of life, and which could give them the opportunity to better express their own needs in terms of services. The provision of information need not be a severe burden on resources and finances. The development of 'resource and information packs' for young carers and their families could provide much of the information - on advice and counselling agencies, benefits, medical information or 'helplines' - that is needed.

The development of such resources, and other new services or arrangements, will need to take full account of the racial, cultural and religious needs of young carers and their families, as our statement of rights reminds us. But they will also have to take account of educational ability and literacy. Some young carers cannot read or write. They will need access to information that is not in written form.

The development of befriending and information services may indeed provide for some of the young carers most pressing needs (Aldridge and Becker, 1994b; Dearden and Becker, 1994). But unless the wider issues concerned with the position of young carers in society are addressed, children will continue to be punished and abused for caring.

Some of these issues are fundamental. 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 sex of the child and the sex of the parent, or the 'ability' or 'maturity' of the child or - like the legal age for marriage, sexual relations, the vote - will it be fixed for all?

**The Responsibilities of Professionals**

To better understand and respond to the needs of young carers and their parents we need, then, to think in terms of rights. But the equation that has 'Rights' on one side must also have 'Responsibilities' on the other: Children who care have rights as children and as carers; parent care receivers have responsibilities for bringing up their children; professionals have responsibilities to work in partnership with both, to support parents as parents, and children as carers. In the Nottingham interviews young carers were very negative about professionals. Comments include:

> My mum had this sort of rash on her bum and it really hurt and they came to deal with it, put a plaster and some stuff on it and mum asked if the nurse could give her a shower. She told my mum there was no point in her coming if she had two daughters who could help. They said they only come to the people who need our help.
>
> The social workers were trying to get a scheme going to say, 'Well we've done it, we've done this and it's working and everything' and it was never working all the time.
>
> When someone goes in and sits and talks to me, like there is social workers coming in sitting and talking to me and they have not been through it and they sit and patronise me ... I will sit there and they will ask me questions and everything and talk to me like I'm a kid - at that point I wasn't a child because I was doing exactly the same things as they were at home.

When they did find out I was looking after him and that he had a brain tumour, social workers didn't really do much about it. Then I was taken to court and threatened to be put into care.

My Guardian Ad Litem was the most vicious person I've ever met. In court she stood up and said, 'I think Jimmy would be best off in care - we'll put him in a secure home'. I've never done a thing wrong in my life - never done anything violent.

We believe that professionals need to:

- **Identify** young carers in their own work settings and environments, for example within schools, social services, health, etc.
- **Acknowledge** the contribution made by young carers, and their strengths and weaknesses.
- **Listen** to what young carers have to say about their experiences and about their needs.
- **Believe** the accounts of children who care.
- **Explain** to young carers the medical problems of parents, in ways which are commensurate with young carers' age and maturity.
- **Assess** the specific needs of young carers. Where children are the primary carers, this should automatically trigger a full assessment of their needs.
- **Recognise** that young carers have needs which may be very different from - indeed can be in conflict with -the needs of their parents.
- **Consult** with young carers about the situations that affect their lives, about their caring roles, about their parents' illness, treatment and services etc.
- **Respect** young carers as partners in caring.
- **Integrate** young carers into existing service provisions, including access to respite care, community care assistance, meals on wheels etc.
- **Develop** appropriate new resources and services for young carers which take full account of the racial, cultural and religious needs of young 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 young carers, group work projects, etc.

- **Provide** young carers with the information that they require to improve the quality of their lives.

- **Include** young carers' needs in future community care plans and charters and children and family plans.

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

- **Protect** young carers as children, and as carers.

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

- **Enable** young carers to develop as individuals and as children by recognising and supporting them.

- **Give** young carers 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 young carers; to improve the quality of their life; to highlight their situation, experiences and needs to policy makers at national and local levels.

The Children's Rights Development Unit has also argued that:

> Compliance with the obligation to recognise the special needs of childhood and to ensure the rights of young carers to play and leisure (Article 31), education (Article 28) and to participate in decisions that affect their lives (Article 12) requires that social services departments, in conjunction with health and education authorities:
>
> - identify those young people within their area who carry caring responsibilities;
> - develop in consultation with young people, comprehensive information about services and benefits available, and how to gain access to them;
> - ensure that all support from professionals takes full account of the contribution being made by the young person and respects their views on service needs;
> - develop support services which reflect the expressed needs of the young people (CRDU, 1994, p.30).

At the frontline, professionals also need to be more aware of the issues involved in families where children are carers and where there is long term illness or disability present (Dearden,

Becker and Aldridge, 1994b). There needs to be agreement between care receiver, young carer and 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 (King's Fund Centre, 1992).

At a practical level young carers' needs must be included in future community care and children and families plans. With the implementation of the NHS and Community Care Act, social services now play the lead role in assessing the needs of carers and users. It is therefore imperative that effective training and assessment procedures are established to ensure young carers are both identified and assessed. Where children are the primary carers, this should automatically trigger a full assessment of their needs as children and as carers.

Service planners and providers will need more awareness, more training, and must be sensitive and proactive - rather than just responding to crises as they arise. And it will also require far better 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. A 1994 report by the Audit Commission into community child health and social services for British children in need found that services are fragmented and poorly co-ordinated. The Commission recommended that joint action between health, social services and education is required to formulate children's services plans, and to deliver needs-based services (Audit Commission, 1994). Agencies need to work together for children who care, rather than against them. The critical question for professionals must be: how can young carers 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 answer is to be found in listening to, telling, and responding to the stories of children who care.

**References**

Alderson, P. (1992) 'Rights of children and young people', in A. Coote (ed.) *The Welfare of Citizens: Developing New Social Rights,* Rivers Oram Press, London**.**

Aldridge, J. and Becker, S. (1993a) *Children Who Care: Inside the World of Young Carers,* Young Carers Research Group, Loughborough University.

Aldridge, J. and Becker, S. (1993b) 'Children as carers', *Archives of Disease in Childhood,* Vol. 69, pp. 459-462.

Aldridge, J. and Becker, S. (1993c) 'Punishing children for caring', *Children and Society,* Vol. 7, No. 4, pp. 277-288.

Aldridge, J. and Becker, S. (1993d) 'Excluding children who care', *Benefits,* No. 7, pp. 22-24.

Aldridge, J. and Becker, S. (1994a) *My Child, My Carer: The Parents' Perspective,* Young Carers Research Group, Loughborough University.

Aldridge, J. and Becker, S. (1994b) *A Friend Indeed: The Case for Befriending Young Carers,* Young Carers Research Group, Loughborough University.

Audit Commission (1994) *Seen but Not Heard: Co-ordinating Community Child Health and Social Services for Children in Need,* HMSO, London.

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

Becker, S. and Aldridge, J. (1994b) 'The price of caring', *Community Care,* 20 January, pp. 18-19.

Bilsborrow, S. (1992) *"You Grow Up Fast as Well" Young Carers on Merseyside,* Carers National Association, Personal Services Society and Barnardos, Liverpool.

Bryman, A. (1988) *Quantity and Quality in Social Research,* Unwin Hyman, London.

Carers National Association (1992) *Young Carers Link,* March.

Carers National Association (1993) *Strategies and Structures: Working with Young Carers Conference Report,* CNA, London.

Children's Legal Centre (1992) 'A children's manifesto', *Childright,* March.

Children's Rights Development Unit (CRDU) (1994) *UK Agenda for Children,* CRDU, London.

Dearden, C. and Becker, S. (1994) *Contacts: A Resource and Information Pack for Young Carers in Nottingham,* Young Carers Research Group, Loughborough University.

Dearden, C., Becker, S. and Aldridge, J. (1994a) 'Children who care: A case for nursing intervention?', *British Journal of Nursing,* in press.

Dearden, C., Becker, S. and Aldridge, J. (1994b) *Partners in Caring: A Briefing for Professionals about Young Carers,* Young Carers Research Group/Carers National Association/Crossroads UK, Loughborough University.

Department of Health (DoH) (1989) *Caring for People: Community Care in the Next Decade and Beyond,* HMSO, London.

Department of Health (DoH) (1990) *Caring for People: Policy Guidance,* HMSO, London.

Department of Health (DoH) (1991) *The Children Act 1989 Guidance and Regulations,* HMSO, London.

Dickens, C. (1857) *Little Dorrit,* reprinted 1985, Penguin, Harmondsworth.

Doyal, L. and Gough, I. (1991) *A Theory of Human Need,* Macmillan, London.

Fallon, K. (1990) 'An involuntary workforce', *Community Care, 4* January.

Gavin, J. (1991) *I Want to be an Angel,* Mammoth, London.

HMSO (1994) *The UK'S First Report to the UN Committee on the Rights of the Child,* HMSO, London.

King's Fund Centre (1992) *Young Carers in Black and Minority Ethnic Communities: Workshop Day Report,* KFC, London.

McLaughlin, M. M. (1974) 'Survivors and surrogates', in De Mause, L. (ed.) *The History of Childhood,* Souvenir Press, London.

Meredith, H. (1991) 'Young carers: The unacceptable face of community care', *Social Work and Social Sciences Review,* Vol. 3, pp. 47-51.

Meredith, H. (1992) 'Supporting the young carer', *Community Outlook,* May, pp. 15-17.

O'Neill, A. (1988) *Young Carers: The Tameside Research,* Tameside Metropolitan Borough Council.

Office of Population Censuses and Surveys (OPCS) (1992) *General Household Survey: Carers in 1990,* OPCS Monitor SS 92/2, HMSO, London.

Office of Population Censuses and Surveys (OPCS) (1994) Official Communication to the Young Carers Research Group.

Page, R. (1988) *Report on the Initial Survey Investigating the Number of Young Carers in Sandwell Secondary Schools,* Sandwell Metropolitan Borough Council.

Parker, G. (1992) 'Counting care: Numbers and types of informal carers', in Twigg, J. (ed.) *Carers: Research and Practice,* HMSO, London.

Parker, G. (1994) *Where Next for Research on Carers?,* Nuffield Community Care Studies Unit, Leicester University.

Twigg, J., Atkin, K. and Perring, C. (1990) *Carers and Services: A Review of Research,* SPRU, HMSO, London.

Twigg, J. (ed.) (1992), *Carers: Research and Practice,* HMSO, London.

World Health Organisation (1982) *Manuals on Child Mental Health and Psychosocial Development,* WHO, Geneva.

# Young Carers in France

## Diarmuid Brittain

### Introduction

There is no direct equivalent in French for the term 'young carer'. In Britain, studies on young carers have focused on their experiences in coping with the physical needs of parents. In France, no literature or unpublished research was found to parallel the British studies. Where French research *has* examined the role of children as carers, it has usually emphasised the child's role in providing emotional rather than physical support to relatives.

### The French Literature

#### *Caring for a Disabled Sibling*

Regine Scelles, a clinical psychologist, has examined the relationship between able-bodied and disabled siblings living in the same household. Her work is based on interviews with social services employees who have been able to cite cases of children involved in providing emotional support and, to a limited extent, physical care to their brothers or sisters (Scelles, 1994a).

One example is given of Julie (10 years of age) who spends a lot of time with her 'mentally handicapped' brother and wishes to learn how to interact more positively with him. Julie wants to be present when the professional involved comes to see her brother. Reasons for Julie's presence, suggested by this professional are: that she wants to learn how to deal with her brother; she wants to see that she is not the only one who fails to establish a rewarding relationship with him; she wants to make sure that the professional is treating him well. Scelles notes that:

> Julie, as the eldest child in the family, has perhaps assigned herself the role of substitute parent, with responsibility for assuring that her brother receives high quality care.

It is also noted that the able-bodied child often tries to emulate the social services professional. One professional in the Scelles study noted that: 'As soon as the door is shut they dive in to care for their brother'.

Julie tends to remain silent while the social services professional is there but other children are known, in the same situation, to ask questions. The professionals involved report that the children have often been primed by their parents to ask questions that they do not necessarily understand. In such circumstances the child can be said to be involved, not only in providing

emotional support to his or her sibling, but also in the role of liaison with the social services, thereby increasing their care-related responsibilities. In answering complex questions adjudged to be mouthed by children but framed by parents, the professionals tend to direct their answers at the parents. Their objective, as noted by Scelles, is 'to remove the child from a problem that is not his concern and which is too complicated for him, and to have the parents take responsibility'. This indicates that the professionals do not deem the role of liaison with the social services as a role to be assumed by children.

Sometimes the professionals adopt the position that it is harmful for able-bodied brothers and sisters to engage in a caring role for their disabled siblings, particularly if they sense that the parent has conferred the caring role on the child.' Such a role substitutes more playful relations between brother and sister and, moreover, if the able-bodied child senses that their caring is not helping the care receiver, the care giver may feel that they are a bad carer or a bad brother/sister. In other cases, the professionals consider that the fulfilment of the caring role can be positive in building the self-confidence of the child (the carer). Thus, the professionals interviewed by Scelles recognise, as do Aldridge and Becker (1993a) in Britain, that the caring role will have negative and positive impacts on children's lives. Scelles indicates that what constitutes 'good' brother/sister relations, and the sort of roles that are acceptable between child siblings, are necessarily arbitrary since social service professionals are having to make judgements without being able to refer to a theoretical framework on brother/sister relationships (Scelles, 1994a; see also Boucher and Frischmann, 1994 for a similar discussion).

***The Child as Translator and Interpreter***

Scelles also highlights the role of the child as translator and interpreter for immigrant parents, the child having learned French at school. This role can move the duty of family spokesperson away from the parent to the child as may be the case when parents prime children with questions to ask social workers. Scelles notes that, as a translator and interpreter, the child will sometimes choose not to translate certain things in order to 'protect' the parent.

***Caring for a Psychotic Mother***

A number of authors in France (Bourdier, 1972; David, 1987; Jardin and Leger, 1986; Merlet and Rottman, 1987; Lamour, 1989) have published analyses of the relationship between infants, adolescents and psychotic parents. These indicate that, due to the psychotic state of the mother, roles are reversed and the child assumes the burden of providing emotional support for their mother. For example, Martine Lamour (1989) observes:

> faced with these mentally unstable, 'absent' mothers, who find it impossible to give and who display particularly regressive needs, we can observe extraordinarily vigilant infants, whose facial expressions are worried and serious, whose physical movement and general

development is inhibited and who are left to console themselves; they behave in this way in order to protect their mother, thereby protecting themselves from harm; in this situation the mother appears to become the infant of a child who has precociously assumed the role of mother. The mother does not adapt to the child but the child to the mother; their relationship is based on **(whole of page 29 missing!)**

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adult. Moreover, if the caring role is taken to impact negatively on the child, the proposition that fathers, rather than mothers, tend to delegate caring to their children (Atkinson, 1992; Aldridge and Becker, 1993a), is supported by the observation that a mother's illness has a particular impact on the child's health (57 per cent children with 3 symptoms or more).[2]

It is important to stress that Menahem's work does not aim to examine the impact of the caring role on children, but it raises the question of why children living with sick or disabled parents should be at such a relatively high risk from health problems in later life. This is a question that may be addressed with reference to the impact of the caring role on children.

## French Welfare Policy and Young Carers

### *Protection for Children*

In France, the framework for child protection is provided through the *Code de la Famille,* the *Code Civil* and the *Code Penal.*

- Child protection is divided into two sectors: administrative and judicial protection. Administrative protection allows for preventative public interventions to protect the child from moral, mental or physical harm.

- Judicial protection is concerned with public interventions that are designed to remove children from situations where they are already in danger or
  where their upbringing is being negatively affected.

### *Administrative Protection*

Under the auspices of administrative protection the state has a responsibility to:

Provide material, educational and psychological support to children under 18, to their families and to those under
21 who are beset by social difficulties liable to harm their well-being (Cooper et al., 1991, p. 51).

Possible provision includes financial help aimed specifically at helping children in need; the intervention of a home help *(travailleuse familiale)* to help (not replace) family members in everyday tasks; the intervention of specialists and social workers *(aide educative)* to help parents and children tackle problems within the family environment; a departmental and national contact service for use by teachers, doctors, neighbours, family members to inform the social services of cases of child abuse.

If a case is drawn to the attention of a public body, an investigation under the auspices of the administrative protection sector is followed by a further investigation by the sector for judicial protection. Any intervention within any family in France is made at the request of the family concerned or at least with its consent.

***Judicial Protection***

The function of this sector is to regulate any child/parent/society conflict that may exist in the civil and criminal domains. The *Juge pour Enfants* has the responsibility of protecting children in moral or physical danger. Cases can be submitted by one or both parents; the prosecutor (or their substitute) who will have been contacted by the social service or the child. Child lawyers are very slowly becoming the norm as judicial representatives of children.

The judge's decision is imparted to the child and the family together and the judge must endeavour to have the family comply with his or her decision. The judge's decision can take several forms, including provision for the parents to enable them to carry out their role as parents (help that can be accompanied by certain obligations); placement of the child outside the family (this can be in an institution or in a foster family).

The social services are legally bound to inform the family of the child's development. The ultimate aim of any placement is to return the child in safety to his or her family. At present, in France, there are around 160,000 children in institutions foster families.

***Children in Danger***

In 1989 legislation was passed to improve the system of detecting child abuse. In 1994 the National Observatory on Decentralised Social Action (ODAS) in France[3] proposed a set of guidelines for detecting cases where a child may be in danger. The guidelines provide definitions of children considered to be in danger. The child in danger is defined as within one of two categories, as follows:

***L'enfant maltraité (abused child)***

> The abused child can be the victim o physical violence, sexual abuse, mental cruelty or grave negligence liable to have serious repercussions for his physical and psychological development (ODAS, 1994, p. 46).

Importantly, the phrase ‘mental cruelty is explained as: 'the repeated exposure of a child to situations where the emotional impact is psychologically harmful' (ibid., p. 47).

Of the various example situations cited the situation where the child ‘assumes tasks that are excessively demanding relative to his age’ (ibid., p. 47) is expressly indicated. It is established in the guide lines that mental cruelty and grave negligence are two factors that can be most readily qualified by examining the behaviour and degree of social adaptation of the child.

***L’enfant en risque (child at risk)***

The child at risk lives in conditions liable to endanger his health, security, morality, education or his develop
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**Protection for Carers**

Research on carers in France dates from the mid 1980s and is exclusively on adult carers of elderly dependants. No attempt has been made to assess numbers of carers in the country. There is, as yet, no equivalent to the British General Household Survey of Carers (Office of Population Censuses and Surveys (OPCS), 1992). Consequently, legislative and policy recognition of carers has been limited. The only survey commissioned to date by a government agency is that undertaken by Duflot and Grignon (1986, in Jani-Le Bris, 1993). This piece of research showed the breakdown of carers by age as follows:
<30 years: 18 per cent; 30-49 years: 23 per cent; 50-64 years: 27 per cent; >65 years: 17 per cent. No figure is available as to the numbers of carers aged below 18 years. The British General Household Survey of Carers records the numbers and characteristics of carers over the age of 16, although it is unable to provide full details of the numbers and characteristics of the 16 and 17-year olds (OPCS, 1994).

Researchers in France have shown that the assistance and services available to carers are far from sufficient. In 1988, Lépine et al concluded that:

> the possibilities on offer are far from corresponding ... to the needs of families and their elderly parents. And the pain of watching a close relative inexorably declining is almost always accompanied by fruitless searches and frantic adaptations for the lack of appropriate services (Lépine and Nobecourt, 1988, in Jani-Le Bris, 1993, p.27’).

Further research indicates that the family tends to believe it is without help and that it has to make do on its own, as best it can (Jani-Le Bris, 1988). Jani-Le Bris also refers to the

intimacy of the care relationship where the carer often feels the caring role to be their own personal domain, a role which cannot be fulfilled by an outside agency.

***Recognition of Young Carers in the Benefit System***

Various allowances are paid to adult carers but young carers, as children (under 18 years), cannot receive any benefit. Allowances available to adult carers include the *allocation familiale* (family benefit) which is paid to a person residing in France, who is responsible for at least two children and the *complement familial* (supplementary family benefit) which is paid to a person who has responsibility for three children all aged over three years. Despite Art. L. 513-1 *(Code de la Sécurité Sociale)* which states that 'family benefits are, in accordance with the rules particular to each benefit, due to the physical person who assumes effective and permanent responsibility for the child', if it is a child who assumes this responsibility they do not accordingly qualify for the receipt of any benefit.

A further benefit available to adult carers is the *allocation de logementfamiliale* (housing benefit) which is paid to a person in whose abode resides a disabled or ill ascendant/descendant, brother/sister, uncle/aunt or nephew/niece who is incapable of work. Even if children could receive family benefits, the chances would be that they could not qualify for housing benefit because it would not be they who owned or rented the abode in question.

Adult carers may also, by dint of their caring role, gain the right to old age and invalidity insurance cover. In order to qualify, the carer must either be caring for a disabled child or a disabled adult in the family home. If the child is a carer, no benefit is accrued because, being under 18, they are unlikely to have had to pay insurance premiums anyway.

The *allocation compensat rice* (compensatory allowance) and the allocation *aux handicapes adultes* are paid to the ill or disabled person themselves by virtue of the fact that their condition requires additional living expenses. The *allocation compensatrice* is paid specifically to allow the recipient to pay for a carer. Payment is conferred if the applicant requires the care of one or more paid carers at home; one or more carers in an institution; one or more of the members of his/her family, if, in providing the care, they are losing earnings. A child aged 16 or 17, who is no longer at school and whose earnings are below a certain ceiling, cannot qualify for this benefit as a carer, since he or she already confers family benefit on their parents. A child providing primary care for a parent or sibling will probably find themselves in the situation where they cannot claim benefit as a carer because the social security system automatically assumes them to be the care receiver, not a young carer.

While carers are recognised in the benefit system, children (aged under 18 years) are not eligible to receive payment of any allowance. Should a child actually be responsible for the care of a relative, the texts that define who shall receive allowances become anomalous. Young carers, therefore, do not derive any financial protection in respect of their caring role.

***Jeunes Filles au Foyer (Young Girls in the Home)***

Until 3 September 1990, a clause existed in the *Code de la Securité Sociale* which recognised girls aged 16 or 17 as young carers. The clause stated that family benefit was to be conferred on parents or siblings of girls aged less than 20 and who 'devote themselves exclusively to household tasks and to the upbringing of at least two children under 14 for whom the benefit recipient has legal responsibility' (CNAF, 1993, p. 278).

Girls who qualified were known as *jeunes flues aufoyer* (young girls in the home). The benefit was at the same level as that paid to parents whose children were at school. While the law did indicate that the benefit would be paid only if the girl concerned was the sister or the legitimate daughter of the recipient, benefits were accorded in respect of girls who were daughters of non-married partners, grand-daughters and nieces. With regard to the requirements for receiving the benefit, the term 'exclusively' was defined as follows:

> [The adverb, 'exclusively' indicates that] the girl has to devote herself to family life in the same way as a mother. But, if she manages, without neglecting her household duties, to devote several hours per week to preparing for her professional future, courses taken by correspondence with this aim in mind will not be considered as a reason not to grant the benefit. However, if she devotes so much time to studying that her assistance to her mother in household tasks does not exceed that which would be normally acceptable if she were a student, or if she were gainfully employed, the benefit will not be accorded (CNAF, 1993, p. 278).

The Ministry of Social Affairs indicated explicitly that if the young girl was attending school the benefit could not be granted.

Prior to 1972, there was no lower limit to the age at which a young girl could obtain leave from school in order to undertake the tasks mentioned above. From September 1972 it was made illegal to grant leave from school to girls who had not reached 16 years.

Article 528 included a number of conditions relative to the mother of the cited children aged under fourteen. It indicated that the young girl in respect of whom the benefit is accorded must live in a household where the mother has an obligation to work; the mother is dead; the mother has left the family home; the mother is physically incapable of carrying out any or all household tasks, because of a prolonged illness or because of the number of children present in the home.

The final condition is of particular importance in so much as it explicitly recognises the situation where a child stays at home to run a household and look after children because of a parent's illness. No reference is made to the child's possible caring duties towards the parent but the benefit is accorded because the mother's illness creates work for the child. The clause

comes much closer to recognising a situation where children look after parents than to seeking to prevent it.

There was an obvious anomaly in the fact that prior to the repeal of article L 528, certain girls aged 16 or 17 were recognised as having all the actual responsibility for other children, without any legal responsibility for them. Moreover, prior to 1972, it was legally acceptable that a girl be exempt from the requirement to attend school until 16, because of caring duties at home.

With the rescinding of article L 528 the anomaly is less explicit. However, the repeal does not signify that children no longer find themselves in this sort of role. Children whose responsibility at home would have accorded allowances to their parents under article L 528, now accord their parents a benefit under article R 512-2 in the *Code de la Sécurité Sociale.* This Article indicates a number of categories of children who may confer benefits on their parent or guardian. It includes children under the age of 18 whose income is not above a fixed limit and this would normally cover children ~previously covered in article L 528. Effectively, because the French government has never repudiated the rationale behind article L 528, it still recognises that girls between the ages of 16 and 18 can be called upon to run a household, undertake primary care of younger siblings and, by tacit recognition, take responsibility for the care of their adult parents.

## Young Carers in France: The Fieldwork

In order to obtain a clearer picture of the French position on young carers I conducted twenty interviews with French policy makers and social service professionals, and interviews with a young carer (aged 6) and his 'dependent' mother, and an ex-young carer (caring since childhood, now an adult).

The interviews with professionals from the social services and from part state-funded associations provided further evidence that French children under 18 years are called upon to provide essential care for their relatives. Moreover, it appears that professionals recognise that in many instances these responsibilities impact negatively upon young carers' psycho-social development.

### *Social and Educational Impact*

The ex-young carer who I interviewed, Sabine, had cared during her childhood for her father, who had polio. Sabine believed that her social development had been negatively affected by her caring role:

> Caring for my father destroyed my teenage years. In that situation there is no such thing as respite.

While Sabine did not indicate that her schooling suffered because of her caring, she did say that her caring tasks left her no time to begin or maintain friendships with schoolfriends in or outside the classroom.

Four of the professional interviewees cited cases that had come to their attention of children missing classes at school in order to fulfil their caring duties at home. In one of these, a girl who was preparing for her baccalauréat was granted leave from school to look after her father who had broken his leg. Although this girl was too old to be legally required to go to school, her career prospects were put in jeopardy by her obligation to care. Furthermore, the professionals involved with these young carers indicated that each, like Sabine, had greatly reduced leisure time and fewer friendships because of their obligation to care.

***Physical Damage***

Sabine indicated that her back trouble (she can no longer do any strenuous lifting) began as a direct result of having to push her father in his wheelchair while she was a child. Furthermore, the young carer who I interviewed, Oumar, aged 6, reported that when his mother, who has muscular dystrophy, falls he tries to help her up, but is not able, and that he cannot wait until he is strong enough to lift her:

> I try to lift mummy when she falls but she is too heavy. I wish I could lift her.

Unless he is instructed in how to lift there is every chance that, like Sabine, he will damage himself physically.

***Psychological Impact***

The French literature revealed that the caring role can psychologically affect the child in a number of different ways. A number of authors have referred to the hyper-vigilance imposed on children by having to look after their psychotically depressed parents. My interviews with French welfare professionals confirmed this. Many of the professionals reported examples where children are ensconced in the responsibility and worry that comes with having to be watchful over, and care for, their parents. One of these children did not have any apparent psychological problems while her psychotic mother was alive but required urgent psychotherapy when her mother committed suicide and she lost her caring role. This and other such cases mirror those portrayed in British studies. Moreover, Sabine, the ex-child carer, indicated that what had been particularly difficult for her had been leaving a role into which she had become socialised, and adapting to a new life without feeling guilty about her diminished caring role. Sabine felt that:

> Children [who care] need to be trained to leave.

Scelles (1994a) has suggested that children should not care for siblings because failure to improve the sibling's condition (often an impossibility) will be misunderstood and construed by the able-bodied child as a personal failure. This can, **it** is suggested, have a negative impact on the able-bodied child's own self-esteem.

Furthermore, it would appear that the caring role can have a negative influence on relations between able-bodied children and their sick relatives. Examples were provided by one professional and compounded through the interviews with the care receiver and the ex-young carer. The professional in question cited examples of children who reacted against their caring responsibilities by abusing their parents, and posed the question: how will this impact on the child's relationship with adults in general? Medina, 36, the care receiver I interviewed, indicated that her son, Oumar, 6, would abuse his position as carer to force his mother to grant him what he wanted:

> It's a perpetual struggle with Oumar. Sometimes our relationship seems based on bribes and compromises.

Sabine, the ex-young carer, indicated that her responsibilities as a carer have served to distance her from her father. She has reacted against her caring role and has decided to live in a house that is inaccessible to her father:

> While I was a child I had too much contact with disability and now I have reacted against it.

**Professional Responses**

There is no explicit policy on young carers within the social services, and young carers are not recognised as a group of either children, or carers with specific needs. However, the majority of professionals from the social services and part state-funded associations (fifteen out of 20 who were interviewed) were able to cite examples of children who had an important role in caring for relatives. Examples included children who were involved in the physical care of relatives, and children who provided important emotional support to relatives.

Two professionals, both psychotherapists, warned against intervention in family affairs, one because she feared further traumatising the young carers and one because she was against the principle of providing too much psychological support. Otherwise, all those who said they had come into contact with young carers saw the situation as potentially requiring some sort of intervention. There was a moral acceptance, especially among social workers, that children should not have to assume heavy caring duties, especially if their caring duties forced them to miss classes at school. Despite favourable attitudes on the part of social workers, policy makers do not, in general, consider that the experiences of young carers, in particular those involved in physical care, are such that public intervention might be beneficial. At present, the only category of child carer to indirectly benefit from public help is the child whose

psychotic parent receives psychotherapy. The child may, in certain circumstances, benefit from psychotherapy in his or her own right but our research indicates that this help only becomes available as a treatment rather than a prevention. Otherwise there seems to be little prospect of any important action being taken to help young carers in France. Indeed, an officer in the *Sous Direction de l'Action Sociale Maine de Paris* (Director's Office, Social Services for Paris) suggested that all they could expect in the way of provision was 'un petit coup de psychanalyse' (a little touch of psychotherapy).

Professionals from the social services and the associative sector do recognise the problems of young carers but tend, especially if they are psychotherapists by profession, to shy away from intervention. Two psychotherapists working with child carers refused to grant access to their patients on the grounds that direct intervention within the caring relationship could only serve to harm the child in question. Another psychotherapist indicated that if she did come into contact with a child carer she certainly would not let the child be interviewed on the subject of their caring role. A further professional, echoing the sentiments of the majority of policy makers, warned against ritualised psychotherapy for children involved in a caring role:

> It is healthy that there are some holes in the net that allow certain cases to slip through ... otherwise we might find ourselves in the midst of a psychological gulag (Psychotherapist at the *Ecole des Parents et des Educateurs).*[4]

Furthermore, three social workers indicated that they could not ask a client to take part in an interview because *asking* would reveal that the professional had broken a code of confidentiality with the client. One social worker who was prepared to ask clients to relate their experiences to me later felt blocked by the guilt experienced by the parent care receivers, and decided that this was too sensitive an area to warrant further investigation.

Evidence from two cases suggests that welfare professionals tend not to get involved unless problems are tangible. In one case a psychotherapist informed me of a girl who looked after her alcoholic, psychotically depressed mother without falling behind at school or showing any signs of maladjustment, until her mother died. At this point the girl became clinically depressed and needed immediate psychotherapy. The interviewee bemoaned the fact that, because there was no obvious cause for concern, no preventative steps had been taken to pre-empt what, in the circumstances, seemed an inevitable mental depression following the loss of her role as carer. My interview with the care receiver, Medina, was also indicative of the reluctance of social service professionals to become involved in cases where children assume important caring roles. Medina, who has muscular dystrophy and is looked after by Oumar, her son aged 6, commented:

> No social worker has ever asked me or Oumar, if he [Oumar] is involved in caring for me.

Somewhat paradoxically, the fieldwork provides evidence that those involved in the caring relationship, both child and care receiver, *would* welcome some degree of outside

intervention. The young carer, the care receiver and the ex-young carer all indicated that they had benefited by being able to talk about their experiences as part of the research process - a finding identical to that of Aldridge and Becker in Britain (1993a). After the end of the interview Oumar, the young carer aged 6, said to his mother: 'I like talking to him [researcher] about you. I want more questions.'

Similarly, Oumar's mother, Medina, said:

> It was good to be able to get a lot of things off my chest. I feel let down by the social services and I need to talk about it.

Sabine also observed:

> I have told you [researcher] a lot of things about my relationship with my father that neither he nor my mother know and I am glad I have been able to do that.

The only agency to officially recognise that young carers may have specific needs has been the France Association for Alzheimer's and Related Problems. This association has held a seminar at which young carers were invited to come and share experiences with each other. Otherwise, one social worker did indicate that the problem had been discussed among a number of her colleagues but that as yet no strategy for action had been devised.

**Future Policy for Young Carers in France**

As we have seen, in contemporary French legislation no specific provision is made for young carers. Young carers are not recognised as a particular group with unique needs. However, the expressed needs of young carers (as detailed in studies in Britain, e.g. Aldridge and Becker, 1993a) are accommodated within the French system of child protection. The French system recognises that a child should not undertake tasks that are difficult relative to his/her age. Moreover, the system stresses the need to ensure a child's educational development.

Until 1990, young girls, aged between 16 and 19 years (inclusive) who devoted themselves exclusively to looking after children and performing household tasks, conferred family benefit upon their parent(s). Therefore, until relatively recently, French legislation officially condoned a situation where a child foregoes educational opportunity (albeit, after the end of the legal obligation to attend school) in order to fulfil duties to care at home.[5] In requiring that the mother of the household be unable to care for the children at home, the law tacitly recognised that the child fulfilled an adult role. The law changed in 1990, in so much as *jeunesfllles aufoyer* are no longer specifically recognised, but the political stance is still such that it is acceptable for girls aged 16 or 17 to undertake, to the detriment of their educational development, tasks that are normally associated with adults. My interviews with policy

makers and welfare professionals have provided further evidence of this standpoint. Moreover, children aged 16 or 17 can still obtain leave from school to care for members of their family.

It is unlikely that French policy makers' position on young carers will change to any large extent. There are two principal reasons: firstly, most professionals involved in policy making are complacent with regard to the system of child protection, believing that if the problem of young carers does not arise it must not exist. One professional commented:

> I've never heard of young carers and can therefore only assume that the problem must not exist. The system of child protection must work pretty well (Officer in the *Sous Direction de l'Action Sociale Maine de Paris,* Director's Office, Social Services for Paris).

Secondly, most policy makers tend to emphasise positive non-intervention in family affairs, on one count, to protect family privacy, as required by law, and on another, because they see young carers' experiences as character building. Another professional observed:

> To get involved in this field would not be justifiable. It is necessary to respect the privacy of family life and, moreover, such an intervention would tend to displace the sense of responsibility that family members ought to feel for one another (Officer in the *Direction GénCrale de la Sante* in the *Ministère des Affaires Sociales,* Department of Health in the Ministry of Social Affairs).

There are further grounds for believing that the needs of young carers will continue to be neglected in France. These include:

- ***Organisational Issues:*** One policymaker indicated that within the system of child protection in France there are too many rules and procedures to be respected in order to provide prompt and effective help to children who care. In particular this policy maker brought my attention to a split between the judiciary and the health services which detracts from a co-ordinated stance on child protection. Moreover, the decentralisation of the French system of child protection since 1983 has been viewed with some considerable disquiet owing to the perceived incompatibility of dispersed centres of decision making within such a crucial area of social welfare (ODAS, 1994). It has been argued that decentralisation has not been accompanied by sufficient efforts to enhance co-ordination between departmental social workers and decision makers on the national level.

- ***Mothers' and Children's Rights:*** One social worker drew my attention to the tendency of judges to accord custody of children to mothers even if the mother has a debilitating illness. The example used by this interviewee was a mother with multiple sclerosis who was accorded the custody of her child even though it was clear that the child in question would have to provide primary physical care to the mother within several years. A psychotherapist stated her belief that children involved in contemporary family court cases are treated too

often as adults. She indicated that the tendency to allow children greater involvement in judgements on custody reveals the social services' fallacious expectation that children are capable of making effective long-term decisions in these situations. Moreover, if the child is deemed capable of this sort of decision, suggested this interviewee, the child may also be assumed to be capable of looking after sick or disabled relatives without suffering any harm. This psychotherapist suggested that according greater responsibility to the child may make social workers even more unsure of their particular remit and consequently hesitant to take action when necessary. The principle of family privacy is clearly upheld under French legislation as are directives on child protection. However, it seems reasonable to assume that, in operationalising legislative guidelines, social service professionals will give priority to family privacy rather than child protection, unless a child has a particularly tangible problem.

- ***Parental Fears:*** Conversely, one of the policy makers interviewed was very clear in condemning the social services for their heavy-handed way of dealing with sensitive family issues. She believed that parents feared their children being placed in care as a result of public intervention and that this fear stopped the parents from contacting any social service professional, a fear echoed by British studies, in particular by Aldridge and Becker (1993c). One French social worker indicated that this fear of the social services putting the caring child in care and the parent in an institution did exist but that it was not justified. She said that present day legislation prevented such action taking place without parental consent and that what parents feared and transmitted to their children was a 'brutal image' of the public intervention dating from years gone by.

- ***Parental Preference:*** An officer from the Huntington's Society of France, who was particularly well acquainted with cases of children who care, indicated that parents trained children to be carers but, for fear that their children would leave, they refrained from telling them about the hereditary nature of the illness. The parents indicated to this officer that they felt more independent if their own children looked after them, instead of some outside agency - a finding wholly consistent with Aldridge and Becker's (1994) research on the parents of young carers in Britain. The value that parents place on this perceived independence becomes evident when one considers that these children provide very intimate physical care, including dressing, showering and toileting their parents. Moreover, a child of a parent with Huntington's Disease has a one in two chance of contracting the illness and, in caring, they must also suffer the trauma of seeing what they may become.

- ***Private Territory:*** Jani-Le Bris (1991, in Jani-Le Bris 1993, p. 31) indicates that carers tend to consider the patient as 'private territory'. She suggests that even if assistance is available, a carer may feel that he/she alone knows how to care for the individual concerned and that a duty lies with the carer as partner or sibling to provide the necessary care. Jani-Le Bris also suggests a spouse who cares may feel that the intimacy of marriage is violated if a third party looks after personal hygiene needs. This argument could be

extended to the intimacy of the family and might implicate children as carers in single parent families.

- ***Parents Delegate Caring Tasks to their Children:*** Atkinson (1992), in Britain, has documented evidence of a father delegating care of his wife to his 15 years old son. The father did not feel it was his place to provide intimate physical care to his partner. Aldridge and Becker (1993a) refer to children being 'elected' into their caring role, and then socialised into it. The research in France also provides evidence of parents preferring their child to care rather than themselves. Sabine, the ex-young carer, indicated that:

  > I had to push Dad in the street in his wheelchair because mum was too embarrassed to do it.

  And Medina, the care receiver, said:

  > It is great that Oumar is now big enough to help me if I need help. It means that I don't have to depend on my husband.

- ***The French Research Tradition:*** A number of interviewees indicated that research into young carers was foreign to the traditional remit of social researchers in France, and typical of that in Britain. One researcher explained that research into the needs of young carers, as 'hands-on', polemic work was viewed in France as outside the domain of research. She indicated that research in France is mainly conducted through government agencies and that the tradition among researchers is to accord priority to more theoretical and abstract issues. She suggested that because universities in France are not heavily involved in research, areas of research do not tend to change and evolve but rather, remain more or less static.

- ***Young Carers: Who Owns 'the Problem'?:*** Seven policy makers were questioned on young carers. All were directly involved in formulating social policy at a national level. None of those questioned had heard of the term 'young carer' and all had difficulty imagining what such a term could represent in France. This lack of understanding was reflected in the fact that none of those interviewed saw the problem as relevant to their field of work. Those with responsibility in social policy indicated that they viewed it as a clinical health problem and those who worked in the field of health protection saw it as a 'problem for the social scientists'. Some professionals saw the question as pertaining to policy on the disabled, while others indicated that it pertained to policy for children. Moreover, the interviews revealed that among those who *can* conceive of young carers, there is a split between those who see them as children involved in providing physical care and those who see them as children providing emotional support. Reflecting this divergence some professionals see provision for young carers as the remit of the psychoanalyst while others see it as the domain of the social worker.

- ***Underfunding:*** A charge levelled at the state by many welfare professionals is that of underfunding but one area that attracted particular criticism from two of the interviewees is the *Service de Sante Scolaire.* This service has a very important role to play in the detection of cases of child abuse (whatever form that abuse may take) and it is claimed that the service simply does not receive enough money to train its personnel to fulfil its mandate. Furthermore, it is claimed that the Ministry of Justice is severely hampered by underfunding and that insufficient pay incentive has contributed to the current critical shortage of social workers (20 per cent of jobs unfilled in 1991) (Cooper et al, 1991).

**Some Concluding Remarks**

Policy makers in France do not officially recognise the needs of young carers. Therefore, it seems reasonable to propose that their needs will not be developed as an area of particular political or social importance, at least in the immediate future.

The French fieldwork has provoked questions about the acceptable level of tasks and responsibilities that can be performed by children. It is clear that personal experience is particularly influential in defining expectations of children and, in any given society, few issues are more contentious than the question of how best to raise a child. In France, the conflictual nature of this question is reflected in anomalous legislation that seeks to protect children from tasks which are too demanding for their age, while tacitly approving of children fulfilling onerous caring roles at home. Moreover, the conflictual quality of the question is apparent in the divergence of opinion between top level policy makers, on one hand, who feel that young caring is character building, and the majority of welfare professionals, on the other hand, who would advocate some form of intervention to protect child carers.'

Policy directives also change with time. Prior to September 1972, a girl's caring duty to her family members was deemed as more important than her educational development. From 1972 until 1990 a girl's caring duty to her family members was deemed more important than her educational development *after age 16.* Since September 1990, a girl's and boy's education is ostensibly considered as more important than a caring duty to family members, but tacitly, and also by legal precedent, approval is given to situations where boys or girls aged 16 or 17 devote themselves to the care of siblings, at the risk of hindering their educational development.

It is evident that the parameters of childhood are, to a great extent, defined in terms of educational development. The right of the child to educational development is upheld under French legislation but the acceptable minimum level of educational opportunity is not clearly defined. A child is obliged to attend school until the age of 16, but it is only after the age of sixteen that he or she becomes eligible to take the baccalauréat, the exam which is likely to have the greatest bearing on his or her professional future. As knowledge generation expands, individuals need to spend longer in schooling to develop their career potential. Clearly, if a

child leaves school at sixteen to care for a relative, his or her educational development will be negatively affected. Policy makers and social professionals do not provide specific guidelines to clarify when educational development should be sacrificed to care for a relative. Indeed, they seem not to have recognised the importance of the issue.

The scenario where a child's future is compromised by caring duties jars with contemporary moral philosophy, and policy makers in France are loath to give credence to its existence. Given that it is considerably easier to supply politically expedient rhetoric than to make pragmatic value judgements on a child's individual right in relation to family responsibilities, it is not surprising that French politicians avoid the issue of young carers. The result, however, is that legislative declarations on children's and carers' rights become aphoristic and conflictual and fail to provide the appropriate professionals with a mandate to help children who care.

**Notes**

1. In another study, Scelles refers to a child whose mother literally told him he had to become his disabled sister's 'teacher' (1994b, p. 3).

2. In the cases where the mother is ill, Atkinson found that fathers consider the role of providing intimate physical care more appropriate to their children than themselves. This finding is shared by Aldridge and Becker (1993a).

3. The Observatory on Decentralised Social Action, ODAS, works in conjunction with the Ministry of Social Affairs (Ministère des Affaires Sociales, de la Sante et de la Vile), the Ministry of Justice (Ministère de la Justice), the Ministry of Education (Ministère de l'Education Nationale) the Child and Family Institute (L'Institut de l'Enfance et de la Famille, IDEF) and the National child protection helpline (Le Service National d'accueil Teléphonique de l'Enfance Maltraitée, SNATEM).

4. The Ecole des Parents et des Eduacteurs is an organisation partly funded by the state whose role is:

> To help families develop their personal resources and level of knowledge as well as to help individuals and organisations involved in family life and in education to develop a greater awareness of the links that exist between children, adolescents and their environment (Declaration in the monthly magazine,' *L'Ecole des Parents).*

5. The clear majority of well remunerated professions require the baccalauréat (the French equivalent to 'A' levels), which a student becomes eligible to take at age 17 years.

**References**


Aldridge, J. and Becker, S. (1993a) *Children who Care: Inside the World of Young Carers,* Young Carers Research Group, Loughborough University.

Aldridge, J. and Becker, S. (1993b) 'Children as carers', *Archives of Disease in Childhood,* Vol. 69, pp. 459-262.

Aldridge, J. and Becker, S. (1993c) 'Punishing children for caring: The hidden cost of young carers', *Children and Society,* Vol. 7, No. 4, pp. 277-288.

Aldridge, J. and Becker, S. (1994) *My Child, My Carer: The Parents' Perspective,* Young Carers Research Group, Loughborough University.

Atkinson, F. I. (1992) 'Experiences of informal carers providing nursing support for disabled dependants', *Journal of Advanced Nursing,* Vol. XVII, No. 7, pp. 835-40.

Bilsborrow, S. (1992) *"You Grow up Fast as Well" Young Carers on Merseyside,* Carers National Association, Personal Services Society and Barnardos, Liverpool.

Boucher, N. and Frischmann, M. (1994) "Paroles d'enfants" - La fratrie de l'enfant atteint d'une maladie neuro-musculaire', *Myoline,* No. 12, p. 3.

Bourdier, P. (1972) 'L'hypermaturation des enfants de parents malades mentaux. Problèmes cliniques et theoriques', *Revue Fran çaise de Psychanalyse,* Paris, No. 1, pp. 19-42.

Carers National Association (1992) *Young Carers Link,* March.

Cooper, A. et al. (1991) *La protection de l'enfance en Angleterre et en France. Elements de comparaison entre les deux systèmes,* Association Jeunesse, Culture, Loisirs, Technique, Beauvais.

CNAF (1993) *Statistiques prestations familiales,* CNAF, Paris.

Dalloz (1993a) *Code de la Sécurité Sociale, Mutualité Sociale Agricole, Code de la Mutualité,* Dalloz, Paris, l9ème éd.

Dalloz (1993b) *Codes de la Sante publique, de liz Famille et de l'Aide sociale,* Dalloz, Paris.

David, M. (1987) 'Souffrance due jeune enfant exposé a un état psychotique maternel', *Perspectives psychiatriques,* Par No. 6/I (nouvelle série), pp. 7-22.

Jardin, F. and Léger, E-M. (1986) 'Etre nourrisson de mere psychotique', in Garonne, G., Jablensky, A. et Manzano, J eds. *Jeunes parents psychotiques et leurs enfants,* SIMEP, Paris, pp. 105-113.

Jani-Le Bris, H. (1993) *Family Care of Dependent Older People in the European Community,* European Foundation for the Improvement of Living and Working Conditions, Dublin.

Lamour, M. (1989) 'Les nourrissons de parents psychotiques', in Lebovici, S. ani Weil-Halpern, F. eds. *Psychopathologie du bebe,* P.U.F., Paris, pp. 655-674.

Menahem, G. (1992) 'Troubles de sante a l'âge adulte et difficultés familiales dura l'enfance', *Population,* No. 4, pp. 893-932.

Menahem, G. (1994) Personal Communication.

Merlet, A-M. and Rottman H. (1987) 'Maintien des liens avec un parent psychotique et son impact sur le développement du nourrisson. Evaluath sur deux ans d'accompagnement therapeutique', *Perspectives psychiatnique~* Paris, No. 6/I, (nouvelle série), pp. 37-47

ODAS (1994) *L'Observation de l'enfance eu danger: Guide méthodologique,* ODAS, Pan Surveys (OPCS) (1992) *General Household Survey:Carers in 1990,* OPCS Monitor SE 92/2, HMSO, London.

OPCS (1994) Official Communication to the Young Carers Research Group.

Scelles, R. (1994a) 'Pourquoi ai-je si ma! mon frère?', *Dialogue,* No. 124, 2° trim., pp. 79-91.

Scelles, R. (1994b) 'La fratrie de l'enfant suivi et les intervenants de Services de Soins et d'Education Spécialisée a Domicile', *Lien social,* No. 272, Sept., pp. 5-10.

# Young Carers in Sweden
# Arthur Gould

## Introduction

The Swedish welfare state, in spite of the economic constraints of the last few years and attempts by a centre-right government to reverse its expansion, remains b British standards, an impressive institution. The services and benefits it provide are generous and far-reaching. Research into a wide range of social problems and attempts to evaluate the extensive programmes designed to alleviate them are widespread and thorough. Few of the organisations that I contacted, however, had heard of, or had conceptualised, the problem of the young carer. There were even those who clearly felt that Swedish social services were so extensive that the problem could not exist at all. This mad the planning of a two-week study visit **t** Sweden rather difficult.

This chapter will present the results of a number of interviews carried out in April 1994, backed up by some documentary evidence. While it may well be the case that the children of parents with a physical disability in Sweden may rarely have to take on the responsibilities that Aldridge and Becker's work in Great Britain has revealed (Aldridge and Becker 1993, 1994), children of parents who hay substance abuse problems or who are mentally ill, often have considerable practical and emotional responsibilities. It could be that, as in Great Britain, the true extent of the problem may not be revealed until both the authorities and researchers adequately conceptualise it as such.

## The Swedish Welfare State

There are excellent prima facie grounds for believing that Swedish society would not have primary young carers to the same extent as has been revealed in the UK. Sweden is a large country with a small population. It has three large urban areas each populated by a million people. It can hardly be said to have cities, let alone inner-cities. Moreover, the consequence of having a political system dominated by social democratic government~ since 1932 and in which the main party the right has never polled more than 25 per cent of the vote in a general election way which respects their integrity. The Social Services Law of 1980 states that:

> The social welfare committee shall endeavour to ensure that persons, who for physical, mental or other reasons encounter difficulties in their everyday lives are enabled to participate in the life of the community and to live on equal terms with others (Ministry of Health and Social Affairs, 1991, p. 9).

Swedish authorities have gone out of their way to identify, plan for, research into and meet the needs of those unable to provide for themselves.

## Young Carers in Sweden: The Fieldwork

It is perhaps not surprising therefore that the initial reaction to my preliminary enquiries concerning the existence of young people who had primary responsibility for their sick or disabled parents should have been greeted with bewilderment by the Swedish authorities. Some spokespersons for national organisations simply suggested that the problem was non-existent because the front-line services in Sweden were so comprehensive and so well-resourced. Others simply stated their ignorance of the topic, saying that they knew of no research in this area. There were even those who implied that the problem might exist in immigrant families where cultural tradition demanded that children take greater responsibilities in the home but not amongst Swedes.

Two factors led to this small research project making some headway. The first was the realisation on the part of some of those contacted that if there was a problem at all it might exist for young people who had mentally ill parents or whose parents had alcohol and drug problems. While those with physical disabilities in Sweden were well-provided for and there was no stigma attached to seeking help - on the contrary, the authorities positively encouraged the take-up of benefits and services -for mentally ill and substance abusing parents there was a sense of shame and also a worry that the authorities might take their children into care if it were thought that the parents could not cope. Not only were social workers familiar with such cases but it was likely that there was a substantial hidden problem. The second factor was the decision to modify the definition of young carers to include not only 'primary' carers who had almost *sole* responsibility for their parents but also 'secondary' carers who had *substantial* responsibilities for them.[1]

Two social services departments, one serving an area of Orebro and the other a district in Stockholm, offered to help trace professional workers who had experience of such cases and, where possible, the young people themselves. In all, twelve workers were interviewed and four young people. In addition, interviews were carried out with representatives of the National Association for the Handicapped (a voluntary organisation which acts on behalf of those with physical disabilities) and Ersta Vändpunkten (a Christian organisation which provides support for children of parents with drink problems).

The questions put to the young carers and the professionals were based initially upon the semi-structured interview schedules used in Aldridge and Becker's work (1993). Subsequently, they were reduced to four principal areas: (a) details concerning the parents, (b) details about the carers, (c) the help and support received by the carers and their parents, and (d) the additional help and support required. The following section will begin with five detailed case-studies followed by a more general picture.

## Case Studies of Young Carers in Sweden

The following case studies have been selected to provide more detailed examples to illustrate the previous section. They each reflect a quite different set of circumstances, problems and responses.

***Johan, 18***

Johan's mother had been seriously mentally ill for some time. She hallucinated and had been diagnosed as suffering from a mild form of psychosis. She had visits from a psychiatric worker and visited hospital herself from time to time. But she refused to attend a day-centre and would not avail herself of a home help. She preferred to be helped by her sons. Her husband from whom she was divorced, yet who had continued to give some support, had died a year ago. She herself lived on long-term sickness benefit.

Her sons took it in turns to visit her -Johan who was the eldest and the twins who were 17. They cleaned the house, did the shopping and kept their mother company. Johan lived in a young person's hostel and his brothers with their maternal grandmother who claimed expenses from social services. A contact person (see 'Interviews with Carers and Professionals', below) had helped train the twins to do various jobs about the house. Johan felt that his brothers had few people to talk to while Johan's social worker, Inger, described them as shy and undemanding. Johan got on well with both Inger and his school counsellor and took part in group therapy sessions in the hostel but he felt the need for more practical help Most of all he wished that his mother was well and his father alive.

His girl-friend found it difficult to cope with the fact that he had such a big responsibility. He found it difficult to concentrate at school as he was often worried about how his mother was coping. Twice he had to give up his training course at school in painting and decorating to help his mother.

***Henrik, 12***

Henrik lived with his mother who had had a severe alcohol problem and had injected drugs. Her male companion, who visited from time to time, also drank. He was the father of the younger children but not of Henrik. The family had a history of separation, substance misuse and violence. In the last year Henrik's mother had attended a family therapy centre, a large house on a council estate run by Margrit.

Margrit felt strongly that Henrik was having to act as a substitute parent - not only doing the shopping and sending his brother and sister (aged 9 and 6) to school, but taking care of mum when she was in one of her states. He had lost his childhood; he could not concentrate or sit still at school; he had few friends and too little time to play with them. He had always had to be responsible; he was always anxious. Mum had no relatives and few friends; Henrik was rather isolated.

The family therapy centre had tried to help the whole family. Mum had been helped to cope and take more responsibility. This itself had helped Henrik. She was now holding down a job. The family had been taken on a 4-day holiday to a country cottage with another family and two workers. Experiences like this enabled everyone to 'have more air, more space', according to Margrit. Henrik had been given extra support at school. When the mother was able to cope on her own she would be encouraged not to attend the family centre any more, but would be provided with continued support.

***Parwin, 14***

Parwin was the middle daughter of a family of ten Kurdish children of widely differing ages. The mother could speak no Swedish and the father had died two years previously. It was Parwin who held the family together at great personal cost.

She did many of the household tasks, took the youngest child to his nursery, accompanied another to hospital and an older sister to the job centre. Although her Swedish was not that good, she had the role of interpreter and contacted the social worker and others about the family's problems.

Much was being done to help the family. A contact family looked after each of the three youngest children on different weekends; a Kurdish neighbour helped with interpreting tasks; the eldest son was on study assistance; there was a pension for one child and a disability allowance for one of the children who was deaf and had Down's Syndrome; the day nursery teacher had good contact with the family; one sister went to a special school and could contact the school counsellor by phone; the family has a house and furniture provided by the local authority. Parwin's only response was to make further angry demands coupled with accusations of racism. Kristina, the social worker, did not know what to do for the best. Whatever was done, was insufficient. Yet she could see that Parwin was frustrated, desperate and stressed; very much in need of help, but unwilling to accept help for herself. She was impossible to communicate with. She would not discuss her own problems only the family's. Here was an example of a young woman who was going under with the weight of responsibility. She was the principal obstacle to the help that could have been given to her. She was the principal victim of her family's problems.

***Tomas, 11***

Another casualty of excessive responsibility was Tomas whose parents' drink problems, and whose father's violence resulted in him and his brothers being taken into care a number of times. Tomas' role was not one of performing household tasks but of trying to protect his mother and his two younger brothers. Both his social worker and the child psychiatric service claimed that he had had excessive responsibility for one so young. He was last taken into care and fostered two years ago after he had revealed details of his parents' conduct to the

authorities, following a report to the police. His brothers were fostered with another family. They now blame him for the family's problems. He is loaded down with a sense of guilt and responsibility. The damaging impact on his behaviour takes many forms.

He asks his foster mother continuously about his parents' current drinking habits; whether they are fighting or not; where they are and what they are doing. He has few social skills; he eats with his hands; messes his pants (when he suspects that his parents are not visiting because of their drinking); and finds brushing his teeth difficult. His few friendships last a short while since he can only dominate and control other children. He is unable to cooperate or play games by accepted rules.

The worse thing is that he is unable to relate to the foster mother out of loyalty to his real mother. He can't talk about his problems since this would result in a further betrayal of his parents. Tomas has a good foster home, help and support at the local school, psychiatric help, a social worker who encourages the parents to play with him on visits and not simply bring presents. But so far none of this has done much to relieve the distress of a child forced to take on an adult role in a home with no real parents. Tomas is unlikely to survive these early experiences without considerable personal damage.

***Monica, 20***

Monica has survived. She found it difficult growing up with a mother who one minute would be behaving perfectly normally and the next be shrieking manically. Her mother attempted suicide in the mid-eighties, followed shortly after by Monica's own attempt. Monica was finding it difficult to come to terms with mental illness. She did not as a child realise this since the term itself meant little and her mother would not admit to any such problem, let alone seek solutions. Monica's father was often away on business and during such periods she would assume the responsibility of most household chores. When her father finally left, she went with him, but still returned to look after her mother for a few days at a time. These periods would begin well but then degenerate into her mother shouting abuse, complaining about Monica not living with her any more.

After some years Monica could no longer cope with the situation. She has now come to terms with the fact that she does not *have to* be responsible for her mother. She does not *have to* have a mother at all. In this she has been helped by a psychiatrist who she ceased to see once she reached the age of eighteen. Monica claims that teachers and school were of little use to her. The school counsellor would not even listen. What she thinks young people like her need, is the opportunity to discuss their problems in groups, so as to reduce the isolation and uniqueness of the experience. Such groups, she suggested, could be advertised in schools and teachers could play a role in making pupils aware of them. On reflection Monica feels a stronger person because of what she has been through.

## Interviews with Carers and Professionals

### The Parents

In the majority of cases, including the five outlined above, the parents were single women whose husbands had died or had left the family home. The sons and daughters who cared for them did not always reside in the same house. Some of the young carers lived with their fathers, or with foster parents. About half the parents had problems with alcohol and sometimes drugs and about half had a history of mental instability. Many of the parents were reluctant to admit that they had a problem or needed help. They did not wish to discuss their problems or take advantage of help and support that was available. Some had been in and out of care themselves.[2]

### The Young Carers

The carers interviewed, or discussed with the professional workers, were mostly between 11 and 18 years of age; half were male and half were female. All but two cases were Swedish. The tasks and responsibilities they had varied considerably. Some were elementary and practical such as cleaning, cooking and shopping. Others involved being responsible for brothers and sisters. Some were expected to keep their parents company; others felt extreme responsibility and guilt for their parents' condition. Some answered telephone calls for help; others 'protected' their parents from the authorities.

The effects on the carers varied according to the intensity of the caring and their own personal strengths. It was felt by some workers and carers that the caring experience reinforced character and made the carer a stronger person. Some coped with their responsibilities; others were overwhelmed by them. They were often unable to concentrate at school; played truant; pretended to be sick. They found it difficult to form relationships. Where they did, they became domineering and excessively controlling. As their parents became isolated so they too suffered isolation. Shame on their own part or a lack of sympathy on the part of teachers and counsellors led to them being reluctant to discuss their situation. They suffered considerable anxiety and stress. One had attempted suicide. One young man was said to be not at all demanding while another was excessively so. All needed support and help from outside.

#### *Help and Support Provided*

Because all of the cases under discussion were known to the authorities, something was being done to relieve the situation to some degree. But since it has already been suggested that many young carers are 'hidden', it is likely that many are receiving little help or support. The most conscientious and aware of the professional workers were adept and ingenious in making resources available. Resources themselves were rarely seen to be a problem.

Each family involved here was likely to be in receipt of the services of a social worker and/or some form of income support whether sickness benefit, disability benefit or social assistance. Some of the children had been in the charge of a foster family at some point in their lives - for longer or shorter periods of time, voluntarily or compulsorily. A foster family could consist of strangers or close relatives. One young carer was placed with a foster family 30 miles from her home but she was provided with a daily taxi service to enable her to attend her local school.

An important resource in many cases was a *contact person or family*. Under the 1982 Social Services Act it became possible for municipalities to pay small fees and expenses to ordinary members of the community to befriend families or individuals with problems (see Gould, 1988 ch. 5; and Andersson, 1993). This resource could be used in a variety of ways and circumstances. In the situation of young carers, they became a lifeline. Their contact families could be there in case of emergency, to provide recreational opportunities or weekend stays. One carer used her contact family whenever her mother was in a drunken state.

Some of these young carers had received psychiatric help, counselling or had been part of a discussion group to enable them to talk about their problems. Practical assistance was sometimes on offer in the form of a home help, a cleaner, or in the case of a young woman who was having to pay the family bills, an accountant. Immigrant families could be provided with interpreters. Child care facilities were prioritised to relieve the burden on one young carer; while her sister was given the support of a young unemployed trainee on work experience at her school.

Sometimes the support was given in a form which would directly help the young carer, sometimes in an indirect form. By helping the parent to cope better, the child was relieved of some responsibility. One parent was helped to cope by the provision of a social worker whose special task it was to act as a support for women with alcohol problems. Another had been encouraged to visit a day centre which provided family therapy. She was employed at the time of the interview at the centre and was about to embark upon a further education course. One young carer asked her mother's social worker if she could have a social worker of her own, without her mother's knowledge. This wish was granted.

***Help and Support Needed***

Not all of these services were available in every case of course. Some young carers were badly in need of the kinds of support mentioned above. At times it was the practical support that was lacking; at other times some opportunity to talk about their problems. Mention was often given in the interviews of the need for group therapy; the opportunity for young carers to share their concerns with others in a similar situation.

In a general sense, the principal lack would seem to be one of social workers, teachers and counsellors who could understand and respond to the problems faced by young carers. It became apparent by the end of the interviews that many of the professional workers who had volunteered to discuss young carers whom they knew and had tried to help, worked in a particular way. It was sometimes described as the *network* approach.[3] These workers tried to understand the totality of the family situation and were prepared to use any resource within their organisation or within the family's own network - be it neighbours, friends, relatives, teachers - to help and support the young carer, the parent or other members of the family. They were very critical of their desk-bound colleagues. The latter tended to go by the book and dealt with the parent or the child - whichever was their client - on a one-to-one basis, oblivious of the wider context of the problem and unwilling or unable to see beyond the most immediate and obvious forms of help. *Net workers* went out into the community to seek solutions; the *desk-bound* rarely ventured beyond their office.

The need for something to be done was expressed very clearly by a counsellor for the long-term mentally ill. In a letter to the head of her clinic she wrote:

> In the last six months, I have come into contact with many young people related to, mostly the children of, psychiatric patients. All these 'children' live under enormous pressure with a huge burden of guilt and in different ways take a big responsibility for their seriously mentally ill parents ... The young people would like to have someone to talk to who understands their situation
>
> An important way to support these young people (and thereby their parents/our patients as well) is to start a support and discussion group for them (Sandvall, 1993).

This quotation illustrates the worker's perception that someone other than her client was at risk and that support for one could be beneficial for the other.

**Ersta Vändpunkten**

It was clear from discussions with many of the professional workers that the few examples of young carers discussed represented a much wider problem even if it local authority to find out what support she would receive to enable her to be an adequate parent. She was satisfied with the answers she received and proceeded to bear two children. Nothing in her experience has led her to think that her children have experienced responsibilities and tasks in excess of those faced by other children. Indeed this was the view of all those interviewed.

They claimed that there is no shame or stigma in physical disability in Sweden; that they could demand support services and benefits and that the authorities would grant them. Disabled people received adequate home help provision, accommodation attached to special services and round the clock support if necessary. Their homes can be adapted; cars are supplied and adapted; taxis are provided. Disabled parents, they claimed, do worry about their ability to cope and fear the possibility of their children being removed if they cannot -

but such cases are rare. Disabled parents have to work harder to prove to themselves and others that they can manage. Their children did have to help in the home but not in a way which damaged their schooling and their friendships.

They were convinced that there was nothing special about their views. They felt sure that people in a similar situation would confirm what they had said. Mention was made, however, of groups which they felt might have different experiences. Few of their members came from immigrant families. Those with progressively deteriorating diseases and those whose disabilities were the result of accidents were not so well-known to them. They themselves felt that they constituted a minority who were at the top of the hierarchy in terms of their needs being met. While there might be young carers with physically disabled parents, the numbers were likely to be negligible.

The only research report that I found which dealt with the situation of young people with disabled parents confirmed this view (Thomasson, 1991). Two of the case studies presented in the report contained comments of young people about the extent of their own obligations. Beatrice, 17, said:

> I have not helped more at home than others. But I have had to do things other than what children usually do. I've hoovered, but not washed up. I've cut the grass, filled up the car with petrol, changed tyres and such like. [My parents] were careful that I did not help too much.

However, she admitted:

> I think it would have been more difficult if I had had to help my parents with personal things, with dressing for example, or in the shower and on the toilet. I wouldn't have liked that.

Ludwig, 18, explained that:

> Some housework is shared out. I have responsibility for washing up and my stepfather prepares the meals. The home help comes at 7 o'clock every morning and stays as long as is necessary. Sometimes she goes when mum goes to work and sometimes she stays a while and does whatever is needed Mum needs help with dressing and going to the toilet. Usually the home help or my stepfather help with that, but occasionally my sister or I do it.

Nor did the rest of those interviewed feel that they had much more to do than other children (Thomasson, 1991, p.6).

> Of course I have to help a little more but that's not going to kill me.

> Many of my friends have to cook once a week and clean the whole house -I've never had to do that.

One dissenting voice added:

> Used - yes, when your parents ask you to do things they can actually do themselves but prefer not to.

If Swedish health care, social services, education and employment services have for many years made it possible for those with disabilities to lead 'normal' lives, then their position can only have been enhanced by a new law which has enshrined their right, amongst other things, to a personal assistant - paid for by the local authority if employed for less than 20 hours a week and by the social insurance office if for more than 20 hours a week (LSS, 1994). This should make it even less likely that the disabled will need to depend on their own offspring as carers.

**Discussion**

The initial reaction to enquiries about young carers in Sweden was mixed. There were those who thought that such a problem did not exist and there were those who simply admitted to knowing nothing about the issue. Amongst those who were aware of the problem, the consensus seemed to be that it was more likely to be found in families where parents were either mentally ill or misused alcohol or drugs. The stigma felt by such parents and their fear that their children might be removed from them (or they from their children) has led to a hidden, and possibly large, problem.

Few however thought it likely that children with physically disabled parents would be primary or secondary carers. While it may be that the measures and resources available to the physically disabled, coupled with the lack of stigma attaching to claimants, explains the fact that few of those contacted knew of the existence of young carers in such homes, it may also be due to a lack of awareness of the problem. The problem has only recently been conceptualised in the UK and it is only just emerging in Sweden. Why should this be so? I would suggest four factors common to both countries - professional practice, community care, cuts in public expenditure and feminism

Social workers, counselors, family therapists have in the last two decades been encouraged to work with their client's total resources - friends, relatives, neighbours - and to be aware that the causes and consequences of a client's condition go beyond the individual. While some professionals may reject such an approach or simply not be very good at putting it into practice, others have put it into effect with enthusiasm. Where they have don so they have often come across addition problems, in this case, young carers.

It is also likely, as more people are being cared for in the community, that relative generally are likely to find themselves taking on more responsibilities. Sometimes the relative in question will be a young person and on occasions the responsibilities and tasks involved will prove too great.

The emphasis upon community care in both Britain and Sweden has been accompanied by pressure on governments to c public expenditure. Where this occurs it more likely that those in need will not g~ sufficient paid support and find themselves having to rely more and more on their children.

Feminist critiques of social policy have focused upon the role of women in caring. This has helped to break down the euphemisms of *family care* and *informal care* and forced us to ask *who* is doing the caring. We have found that it is often women, who because of their subordinate social role are pressured into caring. It is not surprising to find therefore that young people, another subordinate group in our society, should find themselves in a similar position.

One further reason for at least doubting the judgment of those who claim that the physically handicapped would not need to rely upon their children for care and support, is a report of a national survey 13,000 disabled adults carried out in 198 89. Those who have analyzed the survey data claim that most of those interviewed:

> experienced difficulties in getting a response to their demand for support from their immediate environment and from the social services (Hass and Johnson, 1993 p. 63).

If this is the case then it would not be surprising if from time to time they had to rely heavily upon their children.

**Conclusions**

It is clear that a reliance on young carers less likely to arise in the well-resourced Swedish welfare state than in the dilapidated British system. However, young carers do exist and their problems are not always addressed. Moreover, the increasing reliance on community care coupled with expenditure cuts is likely to result in more young carers and more pressure or existing ones. Three issues need to be addressed to alleviate the problem.

First, awareness of the issue needs to be encouraged. This can be done, as in the UK, through publicity, conferences and training. Secondly, the network approach adopted by many Swedish professionals and their agencies, needs to be strengthened. Thirdly, the fear and stigma associated with mental illness and substance misuse need to be reduced if parents with these problems are to be encouraged to rely less on their children. This can only be achieved if the investigative and compulsory powers of local authorities become less threatening.

## Notes

1. The initial definition of primary young carers used was:

> Children and young people (aged under 18), who, in the absence of appropriate practical support from outside agencies, take responsibilities in the care of a relative at home. This might be a parent, grandparent, brother or sister with a disability or in emotional distress. They may be alone in undertaking basic household tasks or full nursing care. In many families, children provide a great deal of emotional stability while the adults are under stress. The effects on children of a parent's long-term illness or disability go largely unrecognised (Carers National Association, 1992). To this, Saul Becker and I added the following definition of a secondary carer:
>
> Children or young people who live with a parent or a relative; whose parent or relative has support from another source (e.g. social services, health care, a voluntary organisation, an adult relative or other adult) but where the child provides a certain degree of help.

2. Not only are some mentally ill adults taken into care in Sweden but there is a law which enables the authorities to take adults who have severe drink and drug problems into care compulsorily. This law was strengthened in 1988 to make it possible to take adults into care for (a) longer periods, and (b) for less urgent reasons (Gould, 1989).

3. One group of social workers has spelled out its philosophy in the following way:

> We work consciously and systematically to disassociate ourselves with the casework tradition which we regard as a game between passive clients and caseworkers who 'know' what people's problems are and how they should be solved. Our starting point is that everyone has the ability to change, wants to take responsibility and that no one wants to be dependent on the authorities. From this systematic approach we want to find out, together with the client, what combined resources and difficulties the client has.

4. While I prefer to use the phrase 'people with alcohol problems', in Sweden it is more usual to refer to 'alcoholics'.

## References

Andersson, G. (1993) 'Support and relief: The Swedish contact person and contact family programme', *Scandinavian Journal of Social Welfare,* Vol. 2, No. 3, Munksgaard, Copenhagen.

Arnell, A. and Ekbom, I. (1994) *När Mamma Eller Pappa Dricker,* Rãdda Barnen, Stockholm.

Aldridge, J. and Becker, S. (1993) *Children who Care: Inside the World of Young Carers,* Young Carers Research Group, Loughborough University.

Aldridge, J. and Becker, S. (1994) *My Child, My Carer: The Parents' Perspective,* Young Carers Research Group, Loughborough University.

Carers National Association (1992) *Young Carers Link,* March.

Esping-Andersen, C. T. (1990) *The Three Worlds of Welfare Capitalism,* Polity Press, Cambridge.

Gould, A. (1988) *Conflict and Control in Welfare Policy,* Longman, London.

Gould, A. (1989) 'Cleaning the people's home: Recent developments in Sweden's addiction policy', *British Journal of Addiction,* Vol. 84, No. 7.

Hass, U. and Jonsson, D. (1994) 'Welfare consequences of the Swedish disability service system', *Scandinavian Journal of Social Welfare,* Vol. 3, No. 2, Munksgaard, Copenhagen.

LSS (1994:1) *Allmãnna Rald fran Socialstyreisen,* Socialstyrelsen, Stockholm.

Ministry of Health and Social Affairs (1991) *Social Services Act and Care of Young Persons Act,* Stockholm.

Nilsson, E. (1993) 'Fortfarande svárt M hjalp for alkoholisters barn', *Svenska Dagbladet,* 14th March, Stockholm.

Sandvall, H. (1993) Official correspondence.

Thomasson, S. (1991) *Va°ra barn och vi,* DHR Stockholmsavdelningen, Stockholm.

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and Potthoff (1993) there might be as many as 72,000 families in which children, although not statistically acknowledged, are potentially as much involved in the care of relatives as are other family members. There may be tens of thousands more who share, to a lesser extent, the care with others within the family.

Almost half of all persons in need of regular care live in households with three or more persons. While 80 per cent of these households state that it is only one person who mainly

provides direct care, very little is known about how far, and in which ways, other family members are affected. Claims that children are not involved in the provision of care have to be qualified. It seems that 'hard' or basic and intimate types of care, such as assisting relatives with washing, dressing, eating, toileting etc., are responsibilities which are primarily taken over by adults or, more precisely, by women. However, other relatives, including children, provide what might be called 'soft' or indirect types of care, such as household work and looking after relatives (sitting services, watching, carrying etc.). Despite the fact that these activities concern the wider family context rather than the immediate need of people cared for, it is important to recognise them as part of the care provided within families.

***Professional Support and Social Services***

The issue of informal care within households is only partially integrated within the existing health care system, which is part of the diversified and fragmented structure of social policy in Germany (see Clasen and Freeman, 1994). As is the case with other sections of the German system, health care is organised around and oriented towards compulsory social insurance. The vast majority of the population are members of one of a multitude of statutory health insurance schemes and (unless they are insured as a dependent relative of a member) pay contributions out of which insurance schemes fund benefits in kind and in cash (see Moran, 1994). For higher earners with incomes above a certain limit there is the option to pay contributions (which are normally higher) to a private health insurance company which provides benefits beyond those offered by statutory schemes.

The entire social legislation in Germany is based on a Social Code and the benefits provided by statutory insurance schemes are painstakingly listed within the Social Code part V, which also regulates care within families. Caring is provided by several types of public, private or voluntary services *(Soziale Trager),* with the voluntary non-profit making sector being particularly strong. A medical assessment of the degree of need, either through the local CP or a doctor in a hospital, determines the entitlement to a particular type of support. This is paid for by the insurance scheme either in cash (to compensate for expenses for a carer chosen by the person in need of care) or in kind, i.e. by providing a carer. The costs to train these carers are borne mainly by voluntary organisations which often receive public subsidies.

This complex interface between public, private and non-profit spheres is typical of the provision of welfare services in Germany (and is becoming a more familiar pattern for those in Britain too). While there is an overarching and uniform federal regulation determined by Parliament and the second chamber (representing the federal states), the assessment of need and reimbursement for the provision of care are conducted by health insurance schemes which are administratively separated into regions. Yet the provision of care is the responsibility of locally organised social services, i.e. mainly of large voluntary welfare associations such as the Catholic *Caritas* (which is the biggest association with 320,000

employees), the Protestant *Diakonie,* the Red Cross and the union-sponsored *Arbeiterwohlfahrt* (see Loren.z, 1994). These organisations provide a tightly knit network of **care** centres or welfare centres *(So:ialstationen)* which employ people who provide care for in and out-patients, and also within private households. Currently there are over 4,000 of these welfare centres, each covering regions with populations of between 20,000 and 40,000 people (Wendt, 1993). Depending on the region, there is also a range of additional organisations which, in close co-operation with welfare centres, provide out-patient services such as meals-on-wheels for example. Unlike the co-ordinating role of care managers within the community care model in Great Britain, there is no social service care manager but these welfare associations are left to their own devices to co-operate with and complement each other. Despite various attempts to do exactly that, a lack of co-operation sometimes result in deficiencies and gaps in the supply of care in some areas, and an oversupply in others (Projektgruppe Häusliche Pflege, 1991).

Within this complex, pluralistic structure of social services provision in Germany, the local Youth Departments also need to be mentioned since they are by law (the Child Protection Code) required to intervene whenever children are in danger. Finally, there is the Federal Welfare Law which, acting as a last safety net, provides means-tested assistance benefits for people in need of care for whom costs cannot be fully covered by health insurance schemes or personal assets. The administration of social assistance is conducted by municipal social service departments which also employ social workers who can be part of the overall assessment of need for individual circumstances.

Means-tested social assistance is paid for by federal states, local authorities and municipalities and has traditionally been an important source of public support for infirm and elderly people in Germany who need domiciliary or institutional long-term care. Not least due to the extensive use of means-testing, social assistance is widely regarded in Germany (as elsewhere) as degrading and stigmatising. Furthermore, demographic changes in Germany led to an increase in the proportion of elderly people being in need of long-term care and to a doubling of costs between 1975 and 1985. By 1991, about 40 per cent of overall social assistance spending accounted for this particular type of support (Gotting et al., 1994). Both the stigmatised nature of social assistance and its increasing costs contributed, after a lengthy and drawn out policy process, to the introduction in 1995 of a new compulsory long-term care insurance. Thus, in the future, the risk of being in need of long-term institutional or community care will be covered largely (but not entirely) via non means-tested benefits with levels determined by medically ascertained degrees of need.

As in other social insurance systems, the funding of the new scheme will be based on compulsory contributions levied on earnings up to a certain limit, which are split between employees and their employers. This adherence to existing principles has been repeatedly emphasised by the government, heralding the new scheme as the ‘fifth pillar’ of German social insurance, which is to supplement traditional schemes covering sickness, unemployment, invalidity and old-age pensions and accidents.

For caring relatives who provide domiciliary care, the new care insurance scheme will bring some improvements, such as a remuneration and also contributions paid into carers' statutory pension insurance -in effect a crediting of non-waged care work. However, this crediting is being regarded as insufficient by many commentators and there are other aspects within the new legislation which have attracted criticism. For example, a large number of people in need of care can be expected to continue to need social assistance in order to top up inadequate insurance benefits. While it is too early for an assessment of the implications of the new long-term care insurance, one potential outcome is that the amount of care taken over by and provided within families, compared to institutional care, is going to increase. This makes it likely that more, rather than fewer children, will be involved in the future care of relatives in the community.

## Young Carers in Germany: The Fieldwork

In-depth interviews were conducted with three children who are currently involved in caring for relatives as well as with three ex-young carers who had cared during childhood. Additionally, semi-structured interviews were conducted with representatives of organisations such as social service departments on the federal as well as the state level, voluntary child protection groups, welfare and professional associations, academics, social workers and others. It was interesting to note that the initial reaction by all but three professional respondents was very similar: the problem of young carers was a topic generally unheard of or had never been part of the institution's remit. In total, representatives of 29 organisations were contacted, of which 25 were interviewed: either over the phone only (6), over the phone followed by a questionnaire (7) or in face-to-face interviews (12).

According to professionals and carers interviewed in this study, the range of caring activities taken over, or contributed to, by young carers does not differ greatly from those provided by adults. Looking after relatives, toileting, washing, feeding and other basic and intimate tasks are done by children as well as adults. Children also administer drugs. The amount of time children spent caring in our study ranged between three to ten hours daily - which is, once again, similar to the situation for many adults.

The young carers and ex-young carers stressed that one of the most difficult aspects of caring is the sheer physical burden of having to lift or carry relatives. Although there is evidence of some attempts to provide carers with support (training on lifting techniques etc.) there are indications that professional guidance is most often insufficient or inadequate. As with adults, children have to rely more on 'learning by doing'. With hindsight, it seemed inconceivable to a previous young carer how she managed to assist her grandmother with toileting. Michaela, who provided care when she was 15 years old, commented:

> We did not have a frame allowing her to walk. That's why I had to grip her from behind everytime she had to use the toilet. Once I almost dropped her because I just couldn't hold on to her any longer.

There is another, more psychological impact regarding the relationship between the care receiver and young carer. In the course of time the former might perceive the carer not as their daughter, son or daughter-in-law etc., but rather as the person responsible for providing care. Inge, a social worker, commented:

> The patient is the centre. The carer stops being an individual but is chained to the person in need of care.

Similarly, the person who requires care may increasingly be seen as a patient rather than as a parent. Patterns of familial expectations are likely to change in both cases and these can prevent an adequate or sensitive response to the needs of carers and cared-for. Not recognising the needs of the young carer, the care receiver might be perceived as egotistical or even tyrannical. The young carer may also have problems understanding the care needs of their parent or other relative. These difficulties are the result of a role reversal: an elderly relative or parent who previously represented authority appears as, or may develop into, a dependent person, while the child takes over many of the functions of a 'parent'.

Child carers in Germany are confronting this role reversal with more problems than adult carers, especially when they take over not only the role of care provider, but also the responsibilities of an adult within the family. As in Britain (Aldridge and Becker, 1993), this is associated with the loss of childhood. Contacts with other children of a similar age become less frequent. There is often also an element of shame. Discussing these issues, one German social worker remarked that:

> The children don't bring home friends from school in case they meet the grandma with Alzheimer's disease.

Furthermore, the responsibility of having to care has a negative affect on school attendance and performance. Many young carers try to keep their experiences hidden; admitting there may be problems does not fit with their new role as 'adult'.

Some German professionals claim that this role reversal is not entirely negative. Taking over responsibility can be, according to a head of a social service department, 'emotionally satisfying and give [children] a feeling of self assurance'. Similarly, a previous young carer regarded the provision of care as a 'biographical enhancement'. Michaela, who cared for her grandmother when she was 15, commented:

> You feel like an adult and you have responsibility. Other people take you seriously. You have a task and you are trusted to cope with it. AU you hear the rest of the time is: you can't do this and you can't do that.

The ambiguity about this role reversal remains, however. Growing responsibilities and expectations (from the cared-for) can turn a care situation which initially gave some form of satisfaction into an obligation, bearing heavily on children. For example, all the young carers interviewed as part of this study had doubts as to whether they would be able to cope long-term with the situation they found themselves in. Hanne, who cared for her mother from 16 to 19, observed that:

> I was very afraid of not being able to manage.

Michaela commented:

> One of the hardest things was that I wasn't sure whether I would be able to cope with the responsibility.

Another painful aspect is the shame regarding bodily functions of the person in need of care. Many adults regard the task of having to feed or to wash their own father or mother, or to cope with their incontinence, as an extreme burden. Another problem, also frequently mentioned by many adult carers, is to be 'chained to the household' (Projektgruppe Häusliche Pflege, 1991; Schneekloth and Potthoff, 1993; Mann, 1994). For young carers this can be assumed to be an even greater problem considering the restriction on the time they have to socialise with peers and also the need to develop and use personal space independent of the parental home. A previous young carer recalled that she 'hated' having to 'look after grandma while the others [friends] were having a good time in the swimming pool'.

Children often start being involved in the care of a relative at a critical point in time, such as a threat of a family break-up due to a parent developing an alcohol problem, or when the cared-for person is likely to be taken into institutional care. In order to prevent this and to keep the family together young carers sometimes deny the existence of any problems in the household to the outside world. An ex-young carer who had looked after her mother on her own, commented:

> What was I to do? If I hadn't cared for her she would have been transferred to the hospital and stayed there for ever.

Difficulties to be encountered by both adult and young carers are partly determined by the particular type of illness or disease and by its development over time. A slowly but successively deteriorating state of health due to senile dementia, chronic illnesses, cancer or disability requires different types of attention and care than problems such as addictions, which occur abruptly and oscillate between extreme distress and relatively 'normal' phases.

People with multiple sclerosis need different types of care to those with psychotic or epileptic forms of illnesses. Sudden fits require young carers to act as an ever present 'emergency service'. This can be a severe psychological burden on children who are permanently threatened by the possibility that the mother, for example, might need sudden and immediate assistance. One expert recalled a family who was given a 'baby alarm':

> In case the mother had a fit the young carer dialled a particular phone number. It worked quite well.

As illnesses develop, more responsibility, and burden, is placed on young carers. They need to be permanently present while having to witness the parent's or grandparent's state of health deteriorating. Finally, there are psychological illnesses which put a different kind of pressure on young carers. Michaela commented:

> Sometimes she imagined that thousands of people were in the flat. I was asked to put coffee cups on the table for them. I would say: 'Granny, there is nobody else here.' In the end it was simply too much and I just went along, pretending there actually were other people.

**Discussion**

When considering the problems resulting from having to provide care within the family, attempts to make clear-cut distinctions between caring and non-caring family members are not appropriate. A distinction might be made, however, between direct types of assistance provided to the person in need, and indirect, more organisational types of care, with different family members taking over responsibilities for both types of work at different times. Children participate in general housework (such as emptying the rubbish bin or doing the dishes) in households without relatives in need of care. Yet the 'normal' amounts of these activities tend gradually but steadily to increase in families which provide domiciliary care. The significant difference between these and other families is the need for children to step in because another family member is bound up with the provision of direct care.

Our research in Germany suggests that, in general, the tasks, and difficulties, young carers encounter are similar to those experienced by adult carers. However, additional problems occur since the specific needs of young carers are not met. According to a head of a Youth Service Department: 'Children are restricted in their own development as a person'. In addition to the need for more overall assistance and support for both adult and young carers, there also need to be new forms of support available to young carers in particular. Firstly, there is the need for more information. This requires advice about the adequate treatment of people in need of care, information about mechanical appliances, aids and adaptations to help people to walk, to communicate, to be able to use the toilet etc., and also about the

availability of potential rehabilitation programmes. The latter have remained largely neglected within the sector of informal care.

In Germany, adult as well as young carers, are generally female. The male young carers interviewed for this study gave the impression that their participation in care work was largely determined by the absence of a sister. A former young carer complained that neither her brother nor her father helped in any way with the housework or the care work. Another respondent declared:

> I never thought about it really. It was obvious to me that I as the female grandchild would help with the care. It was a women's thing to do.

Apparently the girls 'internalised' and took on the caring role as a traditional 'normal' female role within families. A social worker explained: 'Girls turn into mothers and mothers don't feel capable of letting go of their responsibility'.

All young carers interviewed said they were able to cope with the tasks they had taken over. Certainly, professional respondents thought that a certain degree of burden is manageable for children, provided that children's developmental requirements are met. A psychiatrist commented:

> It is important for children to have at least a few carefree years before they are involved in caring. These years provide a positive source for long periods.

Such a position implies a warning for professional bodies, to intervene only very carefully. Well meaning but forced professional help might do more harm than good. Many current and previous young carers, as well as professionals, thought that an advisory and psychological type of support, provided by someone who has the trust of the family is far more important than the availability of in or outpatient social services, which often failed to take sufficient account of a family's particular circumstances. A social worker observed:

> It is important that there is somebody available who is able and willing to listen, who is not directly involved with the provision of care.

A transfer of the cared-for person into a residential or nursing home may be the only way to prevent damage to young carers in some cases. Yet the decision in favour of, or against, an institutional solution should not be left to medical or social service expertise alone, but should include a careful and co-operative consideration of all advantages and disadvantages in particular circumstances. An analysis of a variety of potential support systems is needed, as is due weight and consideration to the young carer's views.

Despite the range of professions and organisations contacted, most welfare professionals reacted in very similar ways. A very small number of those questioned (one psychiatrist, one

social worker and two nurses) had previously been confronted with questions concerning the particular problems of young carers. Most had very little awareness of children who care. In order to improve the situation therefore, more information would be required to inform professionals of the needs of young carers. Second, within social sciences, there is the need for a more systematic investigation of the situation of children who care, taking into account both psychological effects and the impact on their socialisation.

Finally, there is the practical need for the introduction of more advice centres, contact points and other support systems (Projektgruppe Häusliche Altenpflege, 1991; Wendt, 1993). These should be introduced for both adults and even more so for children who might encounter particular difficulties in accessing available information, and in making use of individual advice or counselling simply due to their being 'under age'. These contact points should operate in close contact with existing family advice stations. In Germany, the responsibility for the needs of children, including children who care, lies with Youth Departments, the child protection association *(Kinderschutzbund),* social service departments and one or more social service providers. Networking and better co-operation can be part of the solution here, provided of course that the existence and situation of young carers is known to these organisations in the first place, and that adequate support programmes can be devised. By law, co-operation between public and private youth services is required. This should go beyond existing support however, by concentrating more on the person providing care rather than largely on people in need of care. It remains to be seen whether the new care insurance scheme will contribute to better co-operation once it has been implemented. At the moment, there seems to be a real danger that the opportunity for a real improvement in social care has been wasted. Overall, there is a need for some catching up in Germany regarding both the needs of caring relatives in general, and those of young carers in particular.

**References**


Aldridge, J. and Becker, S. (1993) *Children Who* Care: *Inside the World of Young Carers,* Young Carers Research Group, Loughborough University.

Aldridge, J. and Becker, S. (1994) *My Child, My Carer: The Parents' Perspective,* Young Carers Research Group, Loughborough University~

Bracker, M. et a!. (eds.) (1987) *Aitweibersommer. Beitrdge zu den spaten Jahren der Frau,* Kassel.

Bracker, M. et al. (1988) *Die Pflegebereitschaft der Töchter. Zwischen Pflichterfullung und eigenen Lebensanspruchen,* Wiesbaden.

Clasen, J. and Freeman, R. (eds.) (1994) *Social Policy in Germany,* Harvester, Hemel Hempstead.

Deutscher Paritätischer Wohlfahrtsverband (ed.) (1986) *Pflege durch Angeharige. Anforderungen an die Familie - Herausforderungen an die Altenarbeit,* Wuppertal.

Catting, U., Haug, K. and Hinrichs, K. (1994) 'The long road to long-term care insurance in Germany: A case study on welfare state expansion', paper presented to the World Congress of the International Sociological Association, Bielefeld, July.

Lorenz, W. (1994) 'Personal social services', in Clasen, J. and Freeman, R. (eds.) (1994) *Social Policy in Germany,* Harvester, Hemel Hempstead.

Mann, B. (1994) *Problemlagen in der hduslichen Pflege,* Egeisbach.

Moran, M. (1994) 'Health care policy', in Clasen, J. and Freeman, R. (eds.) *Social Policy in Germany,* Harvester, Hemel Hempstead.

Oerter, R. (1987) 'Jugendalter', In Oerter, R. and Montada, L. (eds.) *Entwicklungspsychologie,* (second edition), Munich, Weiriheim.

Projektgruppe Häusliche Pflege (1991) *Hdusliche Altenpflege in GieJ3en. Analyse des Angebots der sozialen Dienste und der Lebenslagen pflegender Angehoriger,* Materialien zur Gief3ener Altenpianung, No.3, Giel3en.

Schneekloth, U. and Potthoff, P. (1993) *Hilfe- und Pflegebedurftige in privaten Haushalten. Bericht :ur Reprasentativerhebung im Forschungsprojekt 'Moglichkeiten und Grenzen selbstandiger Lebensfuhrung',* Federal Ministry for the Family and Senior Citizens (BMFuS), Stuttgart,/Berlin/Cologne.

Socialdata-Studie (Brag, W., Häberle, G. F., Mettler-Meibom, B., Schellhaas, U.) (1980), *Auzalil mid Situation zu Hause lebender*

*Pflegebedurftiger,* Schriftenreihe des Bundesministeriums für Jugend, Familie und Gesundheit, Bd. 80; Stuttgart/Berlin/Koln/Mainz 1980.

Wendt, W. R. (ed.) (1993) *Ambulante Sozialpflegerische Dienste in Kooperation,* Freiburg.

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institution; it is generally believed that elderly and disabled people prefer to remain in their own homes surrounded by friends and relatives (Laroque, 1985), while children tend to feel they have failed socially if they abandon a sick or elderly person to an institution (Jani-Le Bris, 1993).

The long term consequences of de-institutionalisation and privatisation of care are not yet fully known, but research has begun to show that long term caring can have negative effects on carers, who in most cases are women fulfilling their roles as mothers, wives or daughters (Jani-Le Bris, 1993). As shown in the present study, carers are sometimes also young children who, until recently, were not recognised as such and were unable to draw attention to their own personal needs. Little is known about the long term effects on their lives of the responsibilities which they are carrying.

While the feminist literature, particularly in Britain, was quick to recognise that community care policies were detrimental to women and demanded that the role of carer should be re-conceptualised (Ungerson, 1990), the situation of young carers remained invisible in the absence of a lobby to represent their interests. While the load placed on women was considered unacceptable in a context where, despite their increasing participation in economic activity, they still bear the major responsibility for child care, household tasks and caring for elderly people, the burden on young carers is only just beginning to be examined.

Changing attitudes towards the rights and duties of adult care-givers and care-receivers have given rise to a number of questions which are also relevant to young carers (Glendinning and McLaughlin, 1993; McLaughlin and Glendinning, 1994), for example: When caring in the home is taken on by a close relative, can it be considered simply as a 'social duty' or is it a form of work which should be paid for as it is when performed by somebody outside the family? If payment is made for caring should the allowance be paid to the care-receiver, so that s/he can choose whether to pay a relative or somebody else or is it better to pay the carer directly, a third person *(tierce personne,* as described by the allowance paid for that purpose in France)?

The answers to these questions are determined to some extent by the expectations associated with different systems of social protection. The countries under study here represent different welfare models. The German system is based on the notion of employment-related insurance payments and derived corporatist rights, which mean that family members are held responsible by law, subject to a means test, for their children or elderly parents when they are temporarily unable to support themselves due to unemployment, illness or old age (Ostner, 1994). In this context, a possible response is to provide insurance against such a contingency. At the other end of the scale, the Scandinavian system affords an example of universal social protection, whereby the whole population, irrespective of family circumstances and employment status, is covered against all contingencies. France and Britain occupy an intermediate position. In some respects Britain is closer to Sweden in that access to health care is universal and virtually free of charge. France is closer to Germany since almost the whole population is covered by social insurance, and emphasis is on rights earned through insurance rather than through social citizenship (Hantrais, 1994).

Social attitudes towards the family and the place of children in society are also likely to be important factors determining reactions to young carers in different societal contexts: the Swedes, for example, are known to give priority to equality issues and the well-being of children for reasons of social justice; the French focus attention on families as a key social institution and a fundamental social value, while also paying attention to measures enabling couples to combine work and family life; the Germans give priority to the legitimate couple and to the primary role of mothers in the home; and the British attach importance both to respect for privacy and the protection of children at risk but without giving support to working mothers.

**Defining Young Carers in Different National Contexts**

Governments in Britain have been reluctant to intervene directly in the private lives of families except when children are in danger (Children Act, 1989), and in the 1950s Britain was amongst the first countries in western Europe to implement the de-institutionalisation of caring (Ramon, 1987) and to formulate supportive policies to assist carers (Jani-Le Bris, 1993). It is not therefore surprising to find that Britain was one of the first countries where researchers and others have taken an interest in young carers, and where a national organisation, the Carers National Association, set out to address the problem, while an academic body, the Young Carers Research Group, was established to research national and cross-national issues concerned with children who care.

Young carers are not, however, easy to identify~ either in Britain or elsewhere, because they are not an officially recognised category. The 1990 NHS and Community Care Act in Britain does not, for example, make any reference to children who care. According to the Carers National Association (1992), child carers are 'children and young people who, in the absence of appropriate practical support from outside agencies, take responsibilities in the care of a relative at home. This might be a parent, grandparent, brother or sister with a disability or in emotional distress. They may be alone undertaking basic household tasks or full nursing care. Or in many families, children provide a great deal of emotional stability whilst the adults are under stress. The effects on children of a parent's long-term illness or disability go large1~ unrecognised.' Often young carers have sole responsibility for domestic tasks and the caring needs of a relative.

As part of the current study, the research team gained access to young carers in Britain through social workers, educational and medical advisers and home help services. A number of young carers were identified through contact with the families of sick or disabled people: in households where a person requiring care is the only adult present it is likely that a child will be engaged in caring tasks. In other cases another adult may be present but a child may be delegated to carry out the most unpleasant tasks (Atkinson, 1992).

Although it is very difficult to put an exact figure on the number of young carers in Britain, the phenomenon is undoubtedly widespread. Early estimates suggested that there were about

10,000 young carers in Britain, although Aldridge and Becker (1993) have disputed this figure, suggesting that it is a gross underestimate. Recent data suggest that there are in excess of 200,000 carers under the age of 35 who started caring before their sixteenth birthday and that a third of these had been assisting their parents (Parker, 1992, 1994). There will be many thousands more carers who are over 35 and who also started caring in childhood, and many thousands who share caring with another person. However, it is impossible to be more precise about the numbers until government agencies commit themselves to a nationally representative survey.

In France, young carers have not been a focus of attention for researchers, despite provision in the Social Security Code for an allowance to be paid to young girls who looked after younger siblings and undertook household duties where a parent was unable to do so (Article L. 512-4, repealed by no 90-590 of 6.7.90, which took effect on 1.8.90). In 1989, over 1,200 girls aged between 17 and 20 were in receipt of the allowance, compared with some 4,000 in 1980 (data supplied by the Caisse des allocations familiales, Paris). At the official level the state thereby recognised that young girls could be called upon to forgo education in order to perform caring work, but at the same time, under civil and penal law, legislation for the protection of young children empowers the state to intervene to prevent children from being harmed by circumstances which may adversely affect their physical or mental well-being.

French policy makers claim, however, not to be aware of the problem of young carers and do not consider it to be an issue worthy of further research. No attempt has been made to estimate the number of young carers at national level, and no national surveys make it possible to extrapolate how many children are performing primary, or for that matter, secondary, caring tasks. For the purposes of the present study access to young carers and care-receivers was therefore mainly through organisations such as the Association Huntington de France, Association France Alzheimer et Troubles Apparentés or Association pour la Recherche sur la Sclérose en Plaques. Members of these organisations and also psychiatric social workers are very much aware that young carers do exist, but they are often reluctant to identify them for deontological reasons and because they believe that it would be detrimental to the children concerned if they were to be interviewed.

In Sweden, the general view is that social services are so effective that the family of a sick or disabled person would not hesitate to request help and would be certain to receive it. Anyone suffering from a long term illness or disability requiring home care legally has a right to the services of a personal carer. While no stigma is attached to seeking help in cases of physical disability, the situation is different in the case of a mental illness, drug addiction or alcoholism, where children are more likely to be removed from a family environment which is considered unsuitable for their upbringing. No research has been initiated into young carers and no national data are available on the number of children providing care and support for family members. For this study access to young carers and care-receivers was greatly assisted by the co-operation of two social services departments.

In Germany, official documents and research literature rarely mention young carers, who are classified within the general category of relatives with caring responsibilities; there are about 2,500 under-18s who are counted as carers looking after someone in need of regular attention. However, the number of young carers in Germany is likely to be far higher. Dietz and Clasen, in this volume, suggest that as many as 72,000 children may be taking major responsibilities for caring, with tens of thousands more who share, to a lesser extent, the care with others.

None of the four countries studied for this research collect data on young carers. This is not merely a matter relating to definitions or disputes over the measurement of 'primary' versus 'secondary' caring responsibilities. It is largely to do with a lack of awareness in all countries of the issues of young caring. Indeed, the evidence presented in this report suggests that the distinction between primary and secondary caring may not be helpful in a national or cross-national perspective. In Britain, France and Sweden there are very clear data to show that children are involved in the main care of parents, often unaided, while in Germany there is a suggestion that children are more likely to be sharing the care with others, even though they may be involved in intimate forms of caring. What is perhaps of more importance, therefore, is to define young carers not by the level of their caring responsibilities (primary secondary intimate etc.), but rather by the impact that caring has upon their childhood, education and psycho-social development. The young carers studied in this report all live under different welfare systems. Some are the main, sole carer; some share the care with other family members, or with paid welfare professionals. All the young carers, however, experience some restriction on their childhood experience and development. Some elements of the caring experience can have a positive impact, but generally these are combined with negative effects and consequences, which restrict children's ability to participate in many of the activities that are taken for granted by children who are not carers.

It will be interesting to observe whether a country like Sweden, for example, develops innovative supportive projects for young carers in the future as it becomes more aware of the issues involved. Then, the type of welfare regime is likely to be of particular importance. Now, it would seem to be of less significance because Sweden, like the other countries under study, need to work through awareness raising first.

## Characteristics of Young Carers

The findings presented in this report show that young carers are involved in a similar range of tasks and responsibilities in all four countries under study. The British research is the most developed in this respect, with a number of qualitative studies highlighting the experiences and effects of caring on children (Bilsborrow, 1992; Aldridge and Becker, 1993; McLaughlin, 1974). In policy terms, Britain is also more developed, with a number of national organisations, notably the Carers National Association and Crossroads Care, lobbying and developing services for young carers. By mid-1995, for example, there were about 50

initiatives in Britain, many of which provided localised services for young carers (Dearden and Becker, 1995).

In all the countries studied the fear that children might be removed from their family environment was found to be a factor explaining the unwillingness of parents and children alike to talk about their problems to social workers and other services which might have been in a position to help them, although the researchers all found that carers and care-receivers were pleased, even relieved, to be able to discuss their worries with somebody prepared to listen sympathetically.

The consequences of the burden of long term caring on the physical, mental and social well-being of children are not yet fully understood, since most studies of carers have focused on adults (Twigg et al., 1990; Glendinning, 1992). Nonetheless, the findings contained in this report suggest that many young and ex-young carers do experience physical injury as a consequence of their continued lifting of parents during childhood. It is clear also that some young carers require therapeutic interventions during, or after, their caring experience. Research in France is beginning to show what the long term effect may be, as for example in the case of brothers who cared for their sisters, or vice versa, over a long period of mental illness (Scelles, 1994; Boucher and Frischmann, 1994). Indeed, an issue that will develop in importance as more becomes known about young carers, will be concerned with the nature of therapeutic intervention that is most relevant for young carers: social work, psychoanalysis, psychotherapy, counselling etc. In Britain, there is anecdotal evidence to suggest that some young carers are referred to educational psychologists and psychotherapy services because their behaviour is interpreted in pathological ways, rather than as a consequence of, or reaction to, caring responsibilities. In France too, there is already some debate amongst welfare professionals as to the best approach to be adopted.

For many researchers child caring is equated with a form of child abuse or neglect. Children are considered to be at risk, particularly in the case of hereditary or contagious diseases (Harper, 1986; Tyler, 1990; Honigsbaum, 1991; Aldridge and Becker, 1994; Brittain and Becker, 1995), providing legal justification for taking them into care, but arguments are also found to show that the care-giver can derive satisfaction and sense of identity from carrying out his/her tasks. The carers and welfare professionals interviewed in the four countries report a number of ‘positives’ to come out of the caring experience for children, including a sense of self worth and self assurance, character building, and a value placed on caring and family responsibility.

**Convergence or Divergence in National Reactions to the Issue of Children who Care**

In all the countries under study the initial reaction amongst policy makers, researchers, practitioners and the public in general, is to deny the existence of a problem. Evidence that

children are acting as primary carers for sick and disabled parents or siblings is disturbing and difficult to accept in advanced post-industrial societies.

The lack of research in different countries makes it difficult to determine whether the phenomenon is more widespread in one socio-cultural context than another, but it is possible to draw together a few conclusions based on the reactions observed in the four countries under study, and to attempt to locate the findings in relation to the societal frameworks outlined earlier.

In Britain, even if young carers are not identified in official documents, and in the absence of a tradition of explicit family policy, the rights and needs of children and the protection of children have been built into the legal framework: for example the 1969 Family Reform Act and the 1989 Children Act. Children have the legal right to physical and mental well-being, education, leisure and a secure family environment. When children take on responsibility for a sick or disabled person, most of these rights are called into question, and provisions for children at risk are, in theory set in motion. Jo Aldridge and Saul Becker (1993, 1994) have shown that intervention by public authorities is justified but they question the form it takes. The approach of public policy makers is ambivalent: on the one hand, financial support is considered as a social right, but on the other state intervention in the private lives of individuals is stigmatising and can be interpreted as a punishment or a recognition of personal inadequacy. Home care services are well developed but they tend to focus on the sick or disabled person or on adult carers. The communication channels between young carers, parents receiving care and professionals (general practitioners, home helps, nurses and social workers) are often far from satisfactory, and researchers continue to recommend better co-ordination of support services focusing on the needs of children.

In Germany, the emphasis in policy on normative behaviour within the conjugal relationship and the duties which it entails for family members are not tolerant of non-conformity. Adults are held responsible financially for ageing dependants. I institution of care insurance was the out come of a long and arduous process of negotiation and debate, but no reference was made to young child carers. In a social context where recourse to extern~ help from social services bears a stigma and where the cost of private services is prohibitive, the presence of a woman in the home and the notion of family responsibility have tended to make families look inwards and to be reluctant to seek help from outside. In the future it seems likely that intervention from external services will be more readily accept. able with the institution of care insurance based, as it is, on the concept of individual responsibility.

In France and Sweden, where family policies are more explicit and state intervention more readily accepted and legitimised, current provision would, at first sight appear to enable children whose parents are suffering from a long term illness or disability to cope with the situation with out facing the same difficulties as in Britain or Germany. The research for the report carried out in Sweden by Arthur Gould lends support to this view: examples can be quoted of generous and sensitive support for children in their own right when their parents are

suffering from a socially acceptable illness or dis. ability. In cases of mental illness, drug addiction, alcoholism or AIDS, children in all four countries, irrespective of the social protection system in operation or family policy objectives and priorities, are generally unable to find the support they need because of the stigma associated with these conditions.

The evidence in France is less convincing Policy makers seem to prefer to ignore issue, and the legal rights of children appear to be in conflict with public provision of services. As in Britain, users and professionals complain about the lack of co-ordination between legal, social and medical services, and many of the children concerned may not be benefiting from any official support.

Research into young carers has raised a number of important issues, but the reactions to them differ from one country to another in accordance with their socio-political frameworks. In Britain, one of main questions raised concerns the level of responsibility that children should have within the household and the age at which it is reasonable for them to take on caring duties. In France, emphasis has been on the means made available to ensure that a sick or disabled person can be cared for in his/her own home, including hospital care *(hospitalisation a domicile)* so that children should not need to find themselves performing heavy caring duties. In Sweden, where the practical needs of children are catered for to a large extent by social and other services, the emotional needs of children still require attention to help them in situations where they see their parents in a state of physical, mental and moral decay and dependence. In Germany, the question is posed in different terms, since caring has long been considered primarily as a moral and ethical duty for family members. The decision to create a care insurance within the social insurance system, covering the long term care needs of sick and elderly people, reinforces the idea of individual responsibility, thereby releasing the state and families from the burden of providing care.

An analysis of the situation of carers in the European Union at the end of the 1980s by the Foundation for the Improvement of Living and Working Conditions (Jani-Le Bris, 1993), showed that the burden of caring on adults (over 20) was considerable in all member states, whatever their welfare regime, and that it had adverse effects on the physical, mental, social and moral well-being of the individuals concerned. The report emphasised the importance of the support provided by informal family networks and the positive effects it could have, but it also demonstrated the uneven and often mediocre quality of the socio-medical services offered, the difficulty for disabled people and their carers in formulating and communicating their needs and in accepting outside help. The young carers interviewed in the course of the present study clearly have to face similar problems, but they are more often trying to do so in isolation and in the face of a lack of understanding not only on the part of the social services but also within the family environment and family policy more generally.

Until recently the plight of young child carers had not attracted the attention of public policy makers. If Britain has been one of the first countries in the EU to begin to formulate policies to help carers, it is also one of the first to take an interest in young carers, possibly because

they are increasingly being seen as children at risk. Elsewhere child carers tend to be invisible: in France policy is more concerned with supporting the standard (or large) family; in Sweden measures to help families (and particularly working mothers) are so widespread that they almost automatically cover the needs of child carers; and in Germany grown up children are expected to be responsible for their parents.

**Ways Forward: International Implications**

It is clear that the phenomenon of young carers is to be found in all four countries under study, no matter how developed their welfare state, or how explicit or implicit their family policy. It is also clear that the phenomenon of young caring has not hitherto been identified as a cause for concern. This is perhaps changing as researchers highlight the experiences of young carers in different countries, show up deficiencies in current service arrangements in meeting young carers' needs, and identify the long term implications of allowing caring amongst children to continue unrecognised or unchallenged. Awareness raising strategies in all four countries will need to be developed if young carers are to be identified as a cause for concern and action.

The lack of adequate data in all countries hinders the informed discussion of the extent and nature of young caring. Research will need to be conducted to generate, and maintain, more, and better information, to inform policy and service responses. In Britain there is some movement on this. The Department of Health is now considering how best to gather data of this kind, and whether the General Household Survey of Carers, or other nationally representative surveys, can be used to this effect. In France the research may be credited with having generated some interest in the research community and in the specialised associations set up to help the care-receivers rather than the care-givers. The issue had clearly not yet reached the policy agenda.

Welfare professionals in all the countries under study have a strategic role to play in developing public policy and services for young carers. Whether the development of these services will be at the state or local level has vet to be seen. In Britain, where recognition of the problem is most developed, initiatives have sprung up at the local level, receptive to local needs, often financed by statutory health or social service authorities, but provided by the voluntary (not for profit) sector. Young carers in Britain, it seems, prefer to receive help and support, information and other services from professionals in the voluntary sector because there is less threat or danger of families being split up. Added to this is the need, identified in all four countries, for better co-operation, co-ordination and networking between sectors, professions and welfare organisations.

Similarly, there is a need to remove the fear associated with many of the statutory caring agencies. Young carers and their parents in all four countries talked of their fear of social workers and other welfare professionals. Before services are developed at the local level, and

before young carers will want to be identified, work must be done to create a less threatening, and more enabling, environment.

The shape of welfare policy relevant to young carers in each country is largely determined by the legislation concerning children, families and carers. It is this legislation that will need explicitly to recognise the phenomenon of young carers, and determine the appropriate balance between protecting their childhood and welfare, and/or enabling them to fulfil responsibilities as family carers.

Some countries under study may wish to prevent the phenomenon of young caring taking place. Where children are involved in caring, the impact of which deprives them of their childhood, then services need to be developed to help young carers and their parents. At the same time, a preventative strategy may also be developed to reduce the likelihood that some children will be 'elected' or drawn into the caring role, and to reduce the vulnerability of some children in particular (for example, a single child in a family with a disabled or ill lone parent). Preventative work will include family-based work, service development for ill and disabled people and their carers (for example, meals on wheels, community care assistance), as well as more structural work on attitudes and awareness raising. However, there will always be children who fall through any preventative safety net, and these children will also need support and protection.

**An International Response**

Getting this balance right is perhaps the most difficult of tasks, and is at the heart of the matter concerning the relationship between parents and children, and between individuals, families and the state. Clearly, different welfare regimes will determine their own balance. There is, however, a matter of common principle involved here that cuts across national boundaries, namely the rights of all children to a safe and secure childhood. The UN Convention on the Rights of the Child, ratified in all four countries under study, provides a framework to inform not only legislative and policy responses towards young carers in each member state, but also the day-to-day implementation of policies by welfare professionals at the local level.

The Convention consists of 54 Articles which relate to children's rights and the implementation of these rights. Many of these have direct relevance to young carers (Dearden, Aldridge, Newton and Becker, 1994):

- Under Article 2, young carers have a right to be treated in a nondiscriminatory manner. The experiences of young carers highlighted in the four countries under study shows that young carers do suffer discrimination, both in terms of access to information, services and education because of their parents' disabilities.

- Article 3 adopts the welfare principle, which determines that the best interests of the child are paramount.

- Article 4 relates to the duties of states to implement children's rights to the maximum extent within the available resources.

- Article 5 relates to parental roles; states must respect the responsibilities, rights and duties of parents. separated from their families only when it is in the best interests of the child (for example, in cases of abuse o neglect).

- Article 12 allows for the wishes of children to be taken into account, depending on age and maturity, and gives children the opportunity to be heard in any legal proceedings. The evidence presented in this report shows that young carers are rarely allowed to participate in decisions which affect their lives.

- Article 16 respects a child's right to privacy.

- Article 17 requires that a child has access to information, especially information that will promote their well being and physical and mental health. The evidence presented in this report shows that, in all four countrie5 studied, young carers do not have access to information and do not know what help is available. Many are in danger of hurting themselves physically, and the long term implications for their psycho-social development is unknown.

- Article 18 relates to parental support, requiring appropriate assistance to parents and the development of institutions, facilities and services for the care of children and to promote their rights.

- Article 24 is about children's rights to the highest attainable standards of health. Young carers can suffer ill health as a result of their caring role. This may be poor mental health, for example depression, or poor physical health, for example back problems as result of lifting and carrying.

- Article 27 covers children's rights to a adequate standard of living for their physical, mental, spiritual, moral and social development. Young carers are often living in low income household many in lone parent families where sickness or disability reduces the family income, and therefore the standard of living for all family members.

- Article 28 promotes children's rights **t** education and Article 29 states that or of the aims of education should be for children to develop to their fullest potential. The evidence reported in this study indicates that some young carer are unable to make the best use of their educational experiences and opportunities because of their caring responsibilities.

- Article 31 recognises the child's right rest and leisure to engage in play and recreation. The time constraints and duties which young carers carry can make play and recreation almost impossible for them.

In Britain, Aldridge and Becker (1993) have utilised the Convention and other relevant British welfare legislation to suggest, and promote, a set of rights specifically for young carers in that country. These rights have been widely circulated and now inform the approach of many organisations who are developing services at the local level.

The UN Convention provides an opportunity to develop a cross-national framework for securing the rights of children who care. It also provides a yardstick by which policies and services in member states can be evaluated. It is time to place young carers on the international policy agenda.

**References**


Aldridge, J. and Becker, 5. (1993) *Children who Care: Inside the World of Young Carers,* Young Carers Research Group, Loughborough University.

Aldridge, J. and Becker, S. (1994), *My Child, My Carer: The Parents' Perspective,* Young Carers Research Group, Loughborough University.

Atkinson, F. 1. (1992) 'Experiences of informal carers providing nursing support for disabled dependants', *Journal of Advanced Nursing,* Vol. XVII, No. 7, pp. 835-40.

Bilsborrow, S. (1992) *"You Grow up Fast as Well" Young Carers on Merseyside,* Carers National Association, Personal Services Society and Barnardos, Liverpool.

Boucher, N. and Frischmann, M. (1994) "Paroles d'enfants" - La fratrie de l'enfant atteint d'une maladie neuro-musculaire', *Myoline,* No. 12, p. 3.

Brittain, D. and Becker, S. (1995) 'Les enfants soignants: Le cas de la Grande Bretagne', *Les Cahiers dii CTNERHI,* forthcoming.

Carers National Association (1992) *Young Girers Link,* March.

Davis Smith, J. (ed.) (1993) *Volunteering in Europe,* The Volunteer Centre, Berkhamstead.

Dearden, C. and Becker, S. (1995) *The National Directory of Young Carers Projects in Great Britain,* Young Carers Research Group, Loughborough University, forthcoming.

Dearden, C., Aldridge, J., Newton, B. and Becker, S. (1994) *Getting it Right for Young Carers: A Training Pack for Professionals,* Young Carers Research Group, Loughborough University.

Glendinning, C. (1992) *The Costs of Informal Care: Looking Inside the Household,* Social Policy Research Unit/HMSO, London.

Glendinning, C. and McLaughlin, E. (1993) *Paying for Care: Lesson from Europe,* Social Security Advisory Committee Research Paper 5, HMSO, London.

Hantrais, L. (1992a) 'La fécondité en France et au Royaume-Uni et les effets posibles de la politique familiale', *Population,* Vol. XLVII, No. 4, pp. 987-1016.

Hantrais, L. (1992b) 'Les systemes d'aide et de protection sociale a l'épreuve des structures familiales. Le cas du Royaume Uni', *Recherche sociale,* No. 122, avril-juin, *Lesfailles de la protection sociale en Europe,* pp. 113-29.

Hantrais, L. (1994) 'Comparing family policy in Britain, France and Germany', *Journal of Social Policy,* Vol. XXIII, No. 2, pp. 135-60.

Harper, P. (1986) 'The prevention of Huntington's Chorea: The Milroy Lecture 1985', *Journal of the Royal College of Physicians,* Vol. 20, pp. 7-14.

Honigsbaum, N. (1991) *HIV, AIDS and Children: A Cause for Concern,* National Children's Bureau, London.

Jani-Le Bris, H. (1993) *Family Care of Dependent Older People in the European Community,* European Foundation for the Improvement of Living and Working Conditions, Dublin.

Kamerman, S. B. and Kahn, A. K. (1978) *Family Policy: Government and Families in Fourteen Countries,* Columbia University Press, New York.

Laroque, M-F. (1985) 'La protection sociale des personnes âgées', *Revue francaise des affaires sociales,* Vol. XXXIX, Special issue, July-September, pp. 179-95.

Lefranc, C. (1994) 'Households and families in France, Germany and Great Britain: Statistical constructions and national realities', *Cross-National Research Papers,* Vol. IV, No. 1, pp. 17-33.

Lenoir, R. (1991) 'Politique familiale et construction sociale de la famille', *Revue francaise de science politique,* Vol. XLI, No. 6, pp. 781-807.

McLaughlin, E. and Glendinning C. (1994) 'Paying for care in Europe: Is there a feminist approach?', *Cross-National Research Papers,* Vol. III, No. 3, pp. 52-69.

McLaughlin, M. M. (1974) 'Survivors and surrogates', in De Mause, L. (ed.) *Tue History of Childhood,* Souvenir Press, London, pp. 101-81.

Meredith, H. (1991) 'Young carers: The unacceptable face of community care', *Social Work and Social Sciences Review,* Vol. 3, Supplement, pp. 47-51.

Meulders-Klein, M-T. et Thery, I. (sous Ia dir.) (1993) *Les recompositionsfatniliales aujourd'hui,* Nathan, Coil, Essais & Recherches, Paris.

Monnier, A. et Guibert-Lantoine, C. de. (1993) 'La conjoncture démographique: L'Europe et les pays développpCs d'Outre Mer', *Population,* Vol. XLVIII, No. 4, pp. 1043-67.
Office of Population Censuses and Surveys (OPCS) (1992) *General Household Survey: Carers in 1990,* OPCS Monitor SS 92/2, HMSO, London.

O'Neill, A. (1988) *Young Carers: The Tameside Research,* Tameside Metropolitan Borough Council.

Ostner, I. (1994) 'The women and welfare debate', *Cross-National Research Papers,* Vol. III, No. 3, pp. 35-51.

Page, R. (1988) *Report on the Initial Survey Investigating the Number of Young Carers in Sandwell Secondary Schools,* Sandwell Metropolitan Borough Council.

Parker, G. (1992) 'Counting care: Numbers and types of informal carers', in Twigg, J (ed.) *Carers: Research and Practice,* HMSO, London.

Parker, G. (1994) *Where Next for Research on Carers?,* Nuffield Community Care Studies Unit, Leicester University.

Pauti, A. (1992) 'La politique familiale en Suede', *Population,* Vol. XLVII, No.4, pp. 961-85.

Ramon, S. (1987) 'The making of a professional culture: Professionals in psychiatry in Britain and Italy since 1945', *Cross-National Research Papers,* Vol. I, No. 3, pp. 35-49.

Scelles, R. (1994) 'L'incidence psychologique sur les frères et soeurs de la presence d'un enfant handicapé dans la famille', *Dialogue - Recherches cliniques et sociologiques sur le couple et lafamille,* 2ème trimestre, pp. 79-89.

Schuitheis, F. (1990) ‘Familles d’Europe sans frontières: Un enjeu social par dessus le marché’, *Actes du Colloque Families d’Europe sans frontieres,* 4-5 December, 1989, pp. 73-80.

Schultheis, F. (1991) ‘La famille, le marché et l’état providence’, in de Singly, F. et Schuitheis, F. (eds.) *Affaires defamille, affaires d’Etat,* Jarville Ia Magrange, Editions de 1’Est, pp. 33-42.

Schuitheis, F. (1992) ‘Inerties structurelles et ambivaleñces ideologiques: La protection sociale allemande face aux nouveaux <<risques famiiaux~’, *Recherche sociale,* N° 122, April-June, *Lesfailles de la protection sociale en Europe,* pp. 144-57.

Twigg, J. Atkin, K. and Perring, C. (1990) *Carers and Services : A Review of Research,* HMSO, London.

Tyler, A. (1990) ‘Helping the children to cope’, *Combat Newsletter,* Spring, pp. 1-5.

Ungerson, C. (ed.) (1990), *Gender and Caring: Work and Welfare in Britain and Scandinavia,* Harvester and Wheatsheaf, London.

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