



Caring Before Their Time?

Research and Policy Perspectives on Young Carers

Ann Marie Halpenny
and
Robbie Gilligan

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Children's Research Centre

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Chapter One: Setting the Context

Caring for family members is both valued and expected in Irish society. Yet, on the other hand, much informal caring goes unnoticed and is, to some extent, invisible in the development of policy in Ireland. A recent report by Comhairle (2002) highlights the strong tradition of informal care provision in Ireland and indicates that policy changes aimed at ensuring the supply of care services in the future have continued to rely on the model of informal (home-based) care provision (Comhairle, 2002). In this context, informal care refers to personal care and support delivered in person by family members from the household, by family members beyond the household and by friends. While most of these individuals will be adults, a certain proportion will be children and young people under 18 years of age. However, as in the Comhairle report cited, the specific needs of children and young people who take on a caring role in the context of family illness or disability in Irish society are not identified.

In a recent Dáil debate, the Minister of State at the Department of Health and Children, Ivor Callely, pointed out that considerable progress has been made in recent years in improving the situation of informal family carers (Dáil Éireann, 2003). In particular, the Department of Health and Children had made available additional financial allocations to the health boards and the Eastern Regional Health Authority for the purpose of supplying specific help to such carers by way of provision of a respite grant and/or assistance in the home – nurse, care attendants or home help. According to the Minister, €1.27 million was allocated in 1999, a further €1.27 million in 2000, €2.54 million in 2001 and €1.03 million in 2002, totalling over €6 million allocated in the period 1999-2002. The Department also provides separate financial assistance to the Carers Association by way of core funding which, in 2003, amounted to approximately €710,000. A proportion of this provides support to carers, including training programmes.

In one of the few explicit references to the existence and needs of young carers in an Irish context, Multiple Sclerosis Ireland describe young carers as children and young people who are aged between 5 and 18 years old and who help to look after a parent or other family member who is ill or who has a disability (www.msireland.com).

The Budget Campaign forum hosted by the Disability Federation of Ireland (DFI) in July 2003 highlighted the problem of young carers and clearly indicated the need for action at national level to address this problem. In their pre-budget submission 2004, DFI argued that the lack of adequate funding from support services in the community gives rise to the necessity for children to act as either full-time or part-time carers. The organisation has also identified the need for additional funding for community-based services, so that people with disabilities no longer have to be dependent upon their children for basic everyday care.

The present review is a collaborative project between Barnardos and the Children's Research Centre, Trinity College, Dublin. It has emerged in response to growing awareness, both nationally and internationally, of the need to gain insight into the experiences and needs of children and young people who provide primary or secondary care to parents or other close relatives with a chronic illness or physical disability.

Up until the early 1990s, the issue of young carers was largely ignored by researchers, policy makers and practitioners. Aldridge & Becker (1993a) noted the extensive literature discussing the needs and lives of informal carers in the community. The burden and consequences of the tasks of informal carers had been acknowledged and well documented in the literature. However, this was not the case for young carers, whose very existence had remained unacknowledged until the previous decade. One reason put forward to explain this lack of attention is that children themselves might wish to avoid drawing attention to their situation for fear of being separated from their parent and the family falling apart. To date, most of the available research on the issue has been carried out in the UK and Australia.

A primary focus of the present review is the context of sole carer in which children provide care within the home to a parent with chronic illness or physical or mental disability. However, the review will also attempt to provide a focus on contexts which have received less attention such as the experience of children in separated or lone parenting families.

Aims and objectives of review

The aim of this review is to provide a comprehensive summary of existing international and national literature on children as carers or 'young carers' and thereby to identify some key conceptual issues. A further aim of the review is to explore implications for service provision and to identify approaches that show promise for meeting the social, educational and health needs of young carers. The review will address in particular:

- Issues of definition
- Key theoretical perspectives on young carers
- Evidence of needs among young carers
- Outline of programmes and services responding to their needs
- Issues for consideration for a research agenda in this area

The study has been supported and guided by an Advisory Group which had input into the design and writing up of the review. Members of the advisory group are:

Anne Conroy, Head of Service, Barnardos' National Children's Resource Centre

James Doorley, Regional Support Officer - North East, Disability Federation of Ireland

Dr. Eithne Fitzgerald, Senior Research Officer, National Disability Authority

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Dr. Anne Good, Senior Research Officer, National Disability Authority

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Methodology

The primary methodology employed in the present review was identification and analysis of relevant literature involving mostly published work, although some unpublished material accessed through the internet was also included. Most of the literature reviewed originated in the UK, Australia and other parts of Europe. A primary resource for identifying relevant books and journal articles was the work of The Young Carers Research Group (YCRG) at Loughborough University, which was founded in 1992. Literature was also sourced through a number of multi-disciplinary databases, including, for example, the ISI Web of Science database, the Psychology and Behavioural Sciences Collection and Pubmed (National Centre for Biotechnology Information). A number of interesting articles and critical responses to the subject of young carers were also accessed through browsing the literature and on individual websites in the UK. Examples of such websites include the Research in Practice website and the Centre for the Child and Society in the University of Glasgow. Other data sources included many relevant websites, principally in Ireland and the UK. These included, for example, the Carers Association, Multiple Sclerosis Society and the many websites attached to young carers' projects throughout the UK.

In addition to these sources, the members of the Advisory Group provided assistance in identifying and accessing a number of key documents which were included in this review. Finally, the review was also guided and informed by interviews with a small number of key informants. Interviews were carried out with a small number of professionals working in areas related to young carers as, for example, professionals working within MS Ireland, The Carers Association, The Irish Wheelchair Association and the National Forum of People with Learning Disabilities.

Prevalence of carers in Ireland

The most recent estimates of informal carers in Ireland indicates that a total of 148,754 persons aged 15 years and over (4.8% of the total population) provide regular unpaid personal help for a family member or friend with a long-term illness, problem or disability (CSO, 2004). Among these carers, 57,480 are male (3.8% of all males) and 91,274 are female (5.8% of all females). Details are presented in Table 1.1 below.

Table 1.1 Numbers providing unpaid personal help to family member or friend

Age	No. providing unpaid care				Total	% Population 15 years and over
	Male		Female			
	No.	%	No.	%		
15 years of age and over	57,480	3.8	91,274	5.8	148,754	4.8

Source: CSO, (2004)

Carers in the younger age-groups

One of the difficulties with regard to identifying the extent to which young people provide care to a family member or friend in an Irish context is the absence of available statistical data on carers under the age of 15. With regard to available information on carers in the youngest age categories, 2,996 young people between the ages of 15 and 17 years (representing 2% of carers of all ages), provide unpaid personal help to a family member with a long-term illness, health problem or disability¹. Details of these figures are provided in Table 1.2 below.

Table 1.2 Number of young people (15-17 years of age) providing unpaid personal help to family member or friend

No. aged 15-17	% of all carers
2,996	2

Source: CSO, (2004)

Further breakdown of these young carers in Ireland by single year of age indicates a slightly increasing proportion of young carers with increasing age.

Table 1.3 Young carers (15-17 years of age) by single year of age

Age of Carer	No.	% of all carers
15	819	0.5
16	1,037	0.7
17	1,140	0.8
Total	2,996	2.0

Source: CSO, (2004)

¹ UK figures indicate that between 19,000 and 51,000 young people between the ages of 8 and 17 (Office for National Statistics, 1996) provide unpaid care, representing approximately 0.27 to 0.72% of all young people of this age in Britain.

Interestingly, these data on young carers in Ireland indicate that there is very little difference between males and females in the numbers providing care at this age, with males representing 48% of young carers in this age-group and females representing 52%². (However, the census data shows that a gender gap emerges among carers aged over 25, with women accounting for up to 60% of all carers in each age-group.)

With regard to the breakdown in the number of hours of care provided, 2,440 young people aged 15-17, (1.64% of all carers), provide 1-14 hours of care per week. A further 241 young carers, (0.16% of all carers), provide 15-28 hours a week; 109 young people between 15 and 17 years of age, (0.07% of all carers), provide 29-42 hours of care. Finally, 207 young people between 15 and 17 years of age (representing 0.13% of all carers) provide a minimum of 43 hours of care per week. These figures are presented below in Table 1.3.

Table 1.3. Number of hours of unpaid care provided by young people aged 15-17 years

Number of hours care provided	15-17 years of age No.	% of all carers	% of all carers under 18 ³
1-14	2,440	1.64	81.4
15-28	241	0.16	8.0
29-42	109	0.07	3.6
43 plus	207	0.13	6.9

Source: CSO, (2004)

The majority of young carers between 15 and 17 years (81%) provide between 1-14 hours of care per week. However, it is interesting to consider these data in light of the fact that many of the carers in this age-group are likely to be attending school or in formal education at some level and may, therefore, be providing up to 2 hours of unpaid care per day, in addition to school attendance and homework. Equally notable, however, is the clear association between young carers and the minimum number of hours of care provided (e.g. 1-14 hours per week) and the steady rise with increasing age in the proportion of carers providing maximum number of hours care (e.g. 43 hours or more per week). (See Table 1.4)

While 81% of carers in the age-group 15-17 years of age provide the minimum number of hours of unpaid care (between 1 and 14 hours of care per week), this proportion decreases consistently across each age-group with approximately 60% of those in their 20s and 30s providing this level of care and approximately 50% of those in their 40s and 50s providing this level of care. Similarly, only 3% of these young carers provide the maximum number of hours of care (e.g. 43 hours of care and more), while this figure rises to 20-30% of those aged between 20 and 50 years of age and continues to rise to 50% of those aged 65 and over. See Table 1.4 for details of the distribution of hours of care by age of carer.

Table 1.4. Distribution of hours of care by age of carer

Age of carer	1 - 14 hours of care	43 or more hours of care
15-17	81%	3%
18-24	74%	10%
25-34	64%	19%
35-44	61%	23%
45-54	58%	26%
55-65	50%	35%
65+	37%	50%

Source: CSO, (2004)

² UK figures are similar with males representing 46.5% of young carers (5-15 years of age) and females representing 53.5% of young carers in this age-group. Source: UK Office for National Statistics (1996)

³ As there are no census data for children under the age of 15 years, this category includes children aged 15 years and over but under 18 years.

It is difficult to state with precision the extent to which young people in Ireland who provide care may experience educational disadvantage. However, preliminary analysis of data on the highest level of education obtained by young people aged 15-19 years in the general population, indicates that for a total of 5,593 of these young people (representing 1.8% of all young people this age) the highest level of education completed was primary level⁴. However, this proportion is substantially higher among young people who provide care. Specifically, a total of 600 young people providing care, between the ages of 15 and 19 years, indicate primary school as the highest level of education obtained and this represents 11% of all young carers of this age. These figures raise questions as to whether young people who provide care may experience particular difficulties in completing formal education. It is equally possible to suggest that young people who do not complete formal education beyond this point are also more likely to take on substantial caring roles in the family, where these circumstances arise. Further analysis of those carers between the ages of 15 and 17 years, reveals that the majority of these young people (89%) are still in formal education while approximately 7% of these young people are working for payment or profit. Details of the principal economic status of carers between 15 and 17 years of age are presented in Table 1.5 below.

Table 1.5 Carers aged 15-17 years by principal economic status

Age	Principal Economic Status	No	% Carers aged 15-17
15-17 years of age	Working for payment or profit	206	6.9
	Looking for first regular job	48	1.6
	Unemployed	35	1.16
	Student/pupil	2,657	89.0
	Unable to work (permanently sick or disabled)	7	0.2
	Other (inactive)	43	1.49

Source: CSO, (2004)

Data on the household composition of the household containing carers aged 15-17 years of age, indicate that the most frequent household type is that of couples with children, with 78% of these young carers living in this household type. The second most frequent household type containing young carers is that of lone parent households, with 16% of these young carers living in this household type. Details of the household composition of carers aged 15-17 years are presented in Table 1.6 below.

Table 1.6 Carers aged 15-17 years by household composition

Age	Principal Economic Status	No	% Carers aged 15-17
15-17 years of age	Living alone	9	0.3
	Couples without children	9	0.3
	Couples with children	2,356	78.0
	Lone parents with children	437	16.0
	Two or more family units in household	27	0.9
	Non-family households	33	1.1
	Other	125	4.0

Source: CSO, (2004)

⁴ The next educational level categorised after primary level was Junior Certificate which explains the high figure in this category.

The material compiled and presented on disability and carers in the 2002 Census of Population (Central Statistics Office, 2004) provides useful information on the numbers providing informal care, the number of hours for which this care is provided and the educational and occupational backgrounds of those providing care. However, no information was collected in the Census on details of those under the age of 15 providing care. So there is no information available on their numbers, their family context, details of their educational and occupational backgrounds, nor on details of the precise relationships between these young carers and the cared-for person. Without access to such information, there is difficulty in trying to establish the total numbers and social characteristics of young carers using official Irish statistical data.

Data from other Irish sources are limited. One exception is a report entitled *Multiple Sclerosis, Multiple Challenges* (Multiple Sclerosis Ireland, 1996) in which findings are outlined from a regional study carried out in the Southern Health Board region of Cork and Kerry. This study involved a survey of 260 people with Multiple Sclerosis in order to gain greater insight into the needs of people living with MS. A profile of the age of those providing principal care to respondents revealed that 7% of these carers were under 20 years of age.

Prevalence of young carers abroad

Prevalence of young carers in the UK

The most recent estimate of young caring in the UK comes from a summary of analyses of data provided by Aldridge & Becker (2003). According to these accounts, approximately 3 million children under 16 years of age are currently living in families with illness or disability in the UK (Eurostat, 1997). The number of young people between the ages of 8 and 17 years of age falling into the category of young carer in Britain is estimated to be between 19,000 and 51,000 (Office for National Statistics, 1996), representing approximately 0.27 to 0.72% of all young people of this age in Britain. These details are presented in Table 1.7 below.

Table 1.7: Prevalence of young carers in the UK

Age	Classified as young carer (No.)	% of all young people
8-17 years	19,000-51,000	0.27 to 0.72

Source: UK Office for National Statistics (1996)

However, Aldridge & Becker (2003) point out that a survey carried out by the NSPCC in 2002 indicates that approximately 4% of all 18-24 year olds will have regularly cared for an ill or disabled relative during their childhood. In a recent analysis of the health status of young and elderly informal carers in the UK, findings indicated that of all children aged between 5 and 15 years of age, 1.4% provided informal care, including 53,000 boys and 61,000 girls (Doran, Drever & Whitehead, 2003). Of these, 18,000 provided 20 hours of care or more a week and nearly 9,000 provided at least 50 hours. See Table 1.8 for details.

Table 1.8 Number of children and young people age 5-15 years providing care in the UK

Age	No. providing care		% of all children of this age	Minimum 20 hours of care (No.)	Minimum 50 hours of care ⁵ (No.)
	Male	Female			
5-15 years	53,000	61,000	1.4	18,000	9,000

Source: Doran, Drever & Whitehead (2003)

In Scotland, just over 5,000 children under the age of 16 were identified as 'providing care to people within their own home' and this accounts for 3% of all carers (Scottish Community Care Statistics, 2000). However, due to the contested nature of the notion of young carer and to the fact that many young carers are not visible beyond the boundaries of the immediate family, 'head-counts' of young carers are considered to provide little indication of the amount of caring that is involved, or the nature of the caring experience (Cree, 2003).

Prevalence of young carers in other European countries

A cross-national study of young carers was carried out in 1995, which drew together existing material on young carers in Britain, France, Germany and Sweden (Aldridge, Brittain, Clasen, Dietz, Gould & Hantrais, 1993). According to this study, there has been little or no focus of attention on young carers in the research literature in any of these countries with the exception of Britain. At the time of the study, no attempt had been made to estimate the number of young carers at a national level in any of these countries.

In Australia, the 1998 Australian Bureau of Statistics Survey of Disability, Caring and Ageing reported that 388,800 young people under 26 years of age provided care for family members or friends. This constitutes 17% of all carers in Australia and 6% of the population under 26 years of age. Half of these young people were under 18 years of age, with an average age of 12-13 years. Five percent of these young people, representing a total of 18,800 children and young people, were, in fact, the primary carers, providing the main source of informal support with personal care, mobility and communication.

It is difficult to draw comparisons with regard to the prevalence of young carers in different countries, as these data are presented using different age categories. In Ireland, almost 8% of carers are between 15 and 25 years of age and there are no available data on carers under the age of 15. In England and Scotland, approximately 3% of all carers are under 16 years of age. In Australia, definitions of young carers include those up to 26 years of age and 17% of all carers fall into this age category.

Overview of present review

As the primary sources of literature on young carers were in the UK and abroad, the following three chapters of this review focus on setting the context, discussing the impact of caring for young people and presenting service and policy responses to young caring, based on material outside the Irish context. Chapter two of the present review provides an overview of theoretical approaches to the study of young carers. Chapter three outlines some of the contexts and characteristics of young carers and the impact of caring on young people's lives. Chapter four outlines and discusses service and policy responses to young carers abroad. Finally, Chapter five presents an overview of findings on young carers in an Irish context and of other research findings related to the issue of young carers. Chapter six presents conclusions and outlines recommendations for future policy and research development in this area.

⁵ A comparison of the numbers of young carers in Ireland and the UK, providing more than 15 hours of care, suggests that these figures are strikingly similar. For example, while 16% of young carers in the UK carry out 20 hours of caring and more (aged 5-15 years), 21% of young carers in Ireland provide a minimum of 15 hours of care per week. Similarly, almost 8% of young carers in the UK and in Ireland carry out a minimum of 40 hours of caring.

In Summary

- Up until the early 1990s the issue of young carers in Europe was largely ignored by researchers, policy makers and practitioners. To date, most research has been carried out in the UK and Australia.
- A primary focus in the literature on young carers is the context of sole carer, in which children provide care within the home to a parent with chronic illness or physical or mental disability.
- 148,754 persons aged 15 years and over (4.8% of total population) provide regular, unpaid, personal help for a family member or friend with a long-term illness, problem or disability (CSO, 2004).
- The lack of information on carers under the age of 15 in official statistics makes it difficult to establish the numbers and social characteristics of young carers in Irish society.
- 2,996 young people between 15 and 17 years of age (2% of all carers) provide unpaid, personal help for a family member or friend (CSO, 2004).
- While there is little difference between males and females in the numbers providing care at this age (48% males and 52% females), a gender gap emerges among carers aged over 25, with women accounting for up to 60% of all carers in each age group.
- The majority of young carers between 15 and 17 years of age (81%) provide 1-14 hours of care per week.
- The most frequent household types containing young carers are couples with children (78%) and lone parents with children (16%).

Chapter Two: Perspectives on Young Carers Abroad

This chapter provides an overview of some of the most salient themes and concerns reflected in differing theoretical perspectives on young carers. These themes and concerns reflect the complexity of circumstances in which children and young people take on caring roles, the diverse issues which are encompassed in a focus on young carers, and the multiple standpoints from which we can begin to consider how to respond to young carers.

Growing awareness internationally of the issue of young carers

Since the mid-1980s there has been increased awareness in the UK and Australia of the existence of children and young people as carers. Early research attempted to determine the scale of caring by children. One of the most important sources of literature on young carers in the UK is The Young Carers Research Group (YCRG) at Loughborough University. Founded in 1992, much of the work carried out by the Loughborough Group helped to identify the experiences of young carers and provided an opportunity for young carers to describe these experiences from their own perspectives. This group was among the first to carry out a study of parents with an illness or disability who were supported by their children. Other studies have sought to understand the experiences of, or effects on, children in families where a parent has a specific illness or disability, such as Parkinson's Disease, mental health problems, Multiple Sclerosis, and HIV/AIDS.

An acquaintance with the literature surrounding the question of young carers serves to inform and to guide any approach to fulfilling young carers' needs and the needs of their families, taking into consideration the range of perspectives which this area has generated. Much of the available information on young carers at present comes from research originating in the UK and in Australia.

The present chapter begins by presenting some of the definitions of young carers which have emerged in the literature. Theoretical perspectives which frame our understanding of the key issues associated with young carers are then outlined.

Defining young carers

Attempts to find a satisfactory definition of the term young carer are problematic due to the complexity and diversity of circumstances surrounding this role. One of the difficulties associated with defining the role of young carer is that many of their experiences have been, and still remain, private and to a large extent invisible to those outside the family. A particular issue when it comes to recognising young carers is fear – fear on the part of the adult that the young carer will be taken away (MS Ireland, 2003). In addition, there is fear on the part of the young carer that the relative they care for may be transferred to long-term care or a hospital. If the person being cared for has mental health problems or a HIV/AIDS related illness, there may be considerable stigma associated with caring for them (Becker, 1995; Watson, 1999).

Consistent with the widening concept of disability in legislation, the notion of young caring has been extended in the literature to encompass circumstances where parents have a range of issues – physical impairment, chronic or terminal illness, mental health problems and dependence on alcohol or drugs (Becker, Aldridge & Dearden, 1998). Certain factors have been identified which appear to set young carers apart both from adult carers and from other children within families who do not take on caring roles and tasks. Those defined as young carers are generally under the age of 18, although in Australia young carers are defined as being under the age of 26. Young carers are usually providing care in the context of living with chronically ill or disabled parents. The responsibilities of young carers include providing practical and personal care and emotional support to the cared-for person. Providing such care may undermine other aspects of their lives, as, for example, social and educational opportunities, career prospects and health.

Definitions of young carers involve consideration of a number of criteria. Factors such as the amount of caring and whether or not caring is primary or secondary in importance must be considered. Similarly, the question of whether

young people recognise themselves as carers is an important consideration in any definition (Banks, Gallagher, Hill & Riddell, 2002). Problems in defining who counts as a young carer lead to further problems in identifying which children and young people should have their needs assessed.

The Blackwell Encyclopaedia of Social Work defines young carers as:

“Children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision.”

Another common definition is:

“A young carer is anyone under the age of 18 whose life is in some way restricted because of the need to take responsibility for the care of a person who is ill, has a disability, is experiencing mental distress, is affected by substance use (Carers National Association, 1997).”

Thomas *et al.* (2003) developed an alternative definition of a young carer, which they felt was more inclusive than standard definitions and which reflected the difficulties experienced in distinguishing the needs of young carers from the needs of young people with family members who were ill or disabled. In addition, the authors point out that some young people take on caring roles on a temporary basis or in response to changes in circumstances. The definition they propose is as follows:

“A young carer is a child or a young person who is in need of specific services because their life is affected by the need to provide care for a family or household member who has an illness or disability. This may include a child or young person who provides direct personal care to another person, who takes on a supportive role for the main carer, or who undertakes domestic duties as a result of the need for care. It may also include a child or a young person who is denied ordinary social or educational opportunities because of the other person's need for care. These needs may arise on a regular or on an occasional basis.”

The range of potential definitions of 'young carer' presents challenges to those seeking to develop policy responses to their needs.

Theoretical approaches to the study of young carers

In considering the literature on young carers it is important to bear in mind that knowledge and perspectives on this issue have evolved over several decades and within the framework of differing theoretical paradigms. In attempting to build a comprehensive picture of the contemporary young carer, it is useful to reflect on the views arising from each of these paradigms as they have different implications for both policy and professional practice with ill or disabled parents and children. Changes in our conceptualisation and understanding of terms such as 'disability', 'caring' and 'childhood' contribute to a shift in emphasis from a focus primarily on outcomes and risks for children as carers to a broader focus, which encompasses young carers as competent social agents.

Four key perspectives on Young Carers (Becker *et al*, 1998)

- The **medical model**, which originated in the early 1950s, is primarily concerned with the impact of ill-health and disability on families, including children.
- The **young carers perspective** originated in the late 1980s and early 1990s and is concerned specifically with children who are care-givers within families where there is ill-health or physical or mental impairment. This approach is rooted in a children's and carers' rights perspective which views children and carers as fulfilling distinct family and social roles, including being the main providers of care in the community.
- The **social model of disability** dates back to the late 1970s. This approach is primarily concerned with the rights and needs of disabled people and their experiences of 'disabling barriers' including discrimination and exclusion.
- The **family perspective** is still evolving and becoming more clearly defined in service and policy responses to young carers. The family perspective has grown out of the debate between the rights of disabled people and the rights of children who care and is consistent with the principle of UK and Irish policies, emphasising prevention in a family context as opposed to protection.

The following sections present a brief overview of some of the key issues reflected in these differing approaches and perspectives.

The medical literature

According to Becker *et al.*, (1998) the notion of children as care-givers is given only secondary consideration in much of the clinical literature. The medical literature is more concerned with focusing on the disability or illness itself – primarily its effect on the patient and secondly on the rest of the family. Early medical studies focused on the parent's physical or mental impairment, highlighting the negative impacts of parental illness or disability and often viewing physical and mental impairment as a crisis for the family (Arnaud, 1959; Romano, 1976) and for children within these families (Feldman, Case, Towns & Betel, 1985; O'Neill, 1985). Studies concerned more with the impact of parental illness and disability on children focused on maladjustment, behavioural problems and genetic and psychological risk factors while those relating to specific sensory disabilities such as hearing and visual impairment tended to focus on issues of communication and learning acquisition in children (Olgas, 1974).

Changing role patterns in families living with disability or chronic illness have also been identified. As highlighted by Becker *et al.* (1998) children's roles are modified where children take on additional responsibilities in the home (Hillbourne, 1973). Potential long-term effects of children's adoption of caring roles have also been suggested, in terms of school achievement and transition to adulthood. Arnaud suggested that caring led to 'over-compliance' in children and 'loss of emotional spontaneity'. On the other hand, Sturges (1978) has asserted that in the short term, care-giving and providing assistance in the home may have positive effects in that it can provide security for the child and enable the child to feel that they are actively involved in contributing to positive outcomes for the cared-for person. Power (1977) also considered the possibility of positive effects of parental illness on children, but emphasises that in the long term these positive effects can be outweighed by the consequent obstacles to social interaction which might accompany such a role. In contrast, Power (1977) studied adolescents' response to parents with Huntington's Disease and suggested that early caring role assumption can have a positive impact on young people. In these cases, caring for the parent became a source of hope in terms of being able to actively contribute to the potential improvement of the parent's functioning.

These findings reinforce the necessity to maintain a broad focus on the variety of perspectives and approaches informing the issue of young carers. Findings also underline the importance of reflecting on the many contexts in which children take on the role of carer and how these contexts may modify the consequences and effects of these caring roles.

Consistent with this view, Becker *et al.* (1998) draw attention to a shift of emphasis within the clinical literature, from about the mid 1980s onward, to a focus on the moderating effects of social factors on the prospects for children living with parental illness and disability. For example, the availability of appropriate and efficient professional support for parents and children was recognised as effective both in reducing the likelihood of familial mental illness and helping with coping strategies when illness occurred. Much of the work from this period highlighted the inadequacies of previous clinical research in focusing on child maladjustment rather than intervention strategies that might help children. This period of the clinical literature is characterised by greater emphasis on support that is family-centred and reinforces arguments put forward in some of the more recent work on young carers.

The young carers literature

From the early 1990s, recognition has been increasingly given to the role children play in the care and management of parental illness or disability in the home. Recognition of this role is due, in the main, to the work of the Carers National Association and groups like the Young Carers Research Group at Loughborough University. The young carers literature argues that the nature and extent of children's caring roles and responsibilities is inextricably linked to the reasons which lie behind children taking on such responsibility. Factors contributing to children's role as carer include parental illness and disability, family structure, gender and co-residence and the availability and nature of external support. Aldridge and Becker (1997, pp. 4) have argued:

“ the causes of child caring are to be found in the complex interplay between medical and social determinants, not least the disabling barriers engendered in much contemporary social welfare and social services policy, organization and practice. ”

The social model of disability

The social model of disability rejects the devaluing of physical difference and attempts to reconstruct disability as a consequence of social structures and processes (Becker *et al.*, 1998). Restrictions on opportunities and life chances are considered to be a direct consequence of these social processes. Viewed from this perspective, the individual's impairment is considered in the context of the social and environmental factors which create disabling barriers to their participation in society. Within this model, disability is considered as a product of the person's environment and social context, rather than a medical issue or an inherent attribute of the person. This contrasts with more medical and individual concepts of disability, which equate a person's impairment with their disability, without placing it in any broader context.

Disability rights perspective

Becker *et al.* (1998) identify what they term a 'sub-literature' of the social model of disability – which has challenged the work on young carers and has focused instead on the rights and needs of those who have physical or mental impairments. A priority of the disability rights perspective has been to question the validity of defining young carers as a 'welfare category'. Labelling young people who care as such is viewed as undermining the rights of disabled people (Keith & Morris, 1995; Parker & Olsen, 1995). A key response by the disability rights authors to the issue of young carers and how to support them has been that by recognising the rights of disabled parents and fully meeting their needs through comprehensive support services, young caring would not exist.

One of the key issues to be debated in policy and practice on young carers is striking a balance between the rights of ill or disabled people and the rights of children who care. While the disability rights perspective focuses on the needs and rights of disabled people (usually parents), the work of the Young Carers Research Group has emphasised the need to acknowledge the rights of young carers as children and as carers, without undermining the rights of the ill or disabled parent. As highlighted by Becker *et al.* (1998), emphasising young carers' rights as children was a positive move which facilitated the development of appropriate service provision and policy. Not until the debate on young carers emerged in the early 1990s were child carers included in both policy on carers and in the research and literature on informal care.

Family perspectives

Most recently, from the 1990s to the present, there has been a shift in emphasis from a consideration of young carers in isolation to a perspective which considers the caring and support needs within the context of the whole family. In many cases, illness or disability can alter the organisation of the basic care-giving system within families (Altschuler, 1997). This includes the context in which people receive nurturance, stimulation and age-appropriate limit setting – all of which affect the patterns of alliances and boundaries within family relationships. Altschuler (1997) argues that illness places two often contradictory systems of care side-by-side within the family: one of these is based on developmental needs and the other is based on meeting the demands of the illness. For families where children are involved in looking after parents, it is, therefore, important to ensure that one system of care does not negate the second. For example, providing care for a parent should not negate the capacity of a mother or father to parent their child. Decisions on the part of the ill or disabled parent about who to ask for help may be determined by whether requests are likely to be heard, rather than what is age-appropriate. Although each family will find their own method of coping with these challenges it is important to ensure that changes in family organisation do not obstruct access to constructive parenting. Altschuler (1997) also points out that sub-system boundaries may be altered as a consequence of living with illness or disability in a family. When a parent is ill or disabled, an adolescent child or a grandparent may become incorporated into the parental sub-system to meet the needs of younger children.

The value of a family perspective is increasingly evident not only in the literature on young carers but also in policy and service responses to the needs of young carers. Greater prioritisation of the needs of the whole family is reflected in the demand for a revised strategy from one which prioritises issues of protection to one which has a stronger focus on prevention. Promoting a family approach to serve the best interests of young carers and their families emphasises the importance of family autonomy and family rights. It shifts the focus away from children's and disabled people's rights and towards the interactive needs and rights of the whole family.

Challenges to the young carers perspective

Research on young carers has generated some resistance and controversy. Newman (2002) highlights a number of issues which call into question certain attitudes and approaches to the study of young carers. First of all, much of the research on young carers is perceived to focus exclusively on supporting children and young people rather than supporting parents living with illness and disability. Such an approach may be considered to be promoting a return to approaches from the past, which pathologised and distorted images of disabled people (Keith & Morris, 1995). Secondly, there is a need for more robust research on the impact of caring on young people and such research should accompany any efforts to expand services to assist young carers. Thirdly, difficulties and differences surrounding definitions of young carers have complicated attempts to establish the extent to which young caring is prevalent in the UK. Newman (2002) proposes that young carers should be defined on the basis of the impact which their caring has on them, and not just on the duties and tasks which they carry out. If we fail to define young carers on the basis of the impact of their caring on their lives, the distinction between a young carer and a child in any family where there is illness or disability will become increasingly difficult to draw. A fourth point highlighted by Newman (2002) is that there has been little research into the effectiveness of services and projects set up to support young carers. According to the author, not alone is it possible that such services do not actually benefit young carers, but he argues that being labelled a young carer at an early age may result in a weakened locus of control and a sense of being a 'victim' that may persist into adult life.

Challenges to the research on young carers have also highlighted a focus which is exclusively negative on the impact of parental disability on a child's growth, intelligence and adjustment (Newman, 2002; Olsen, 1996). According to this argument, such research provides little real insight into how parental disability and illness affect the domestic and caring tasks of children. Investigations into positive outcomes for children are rare (Coates *et al.*, 1985). Few studies explore how a 'well' child may help their disabled sibling or identify benefits for a child or young person in helping a relative (Lobato, 1983; Leonard, 1991). Yet, a number of studies have found as many positive outcomes for children in helping care for disabled siblings as negative ones (Gallo, Breitmayer, Knafel & Zoeller, 1992; Meyer, 1997; McHugh, 1999). Several studies which have begun from the premise that 'well' children are a potential source of support for their disabled siblings

have concluded that such children have the capacity to be powerful change agents. Similarly, in situations where families are not seriously affected by poverty and marital discord, the *impact* of parental disorders on children is greatly moderated (Emery, Weintraub & Neale, 1982; Buck & Hohmann, 1983; Goodman, Brogan, Lynch & Fielding, 1993).

Banks *et al.* (2001) draw attention to other challenges to the research on young carers. One of these challenges centres on a lack of robust data which would allow some discrimination between different types of caring and a lack of comparative research with other children not in a caring role (Keith & Morris 1995; Olsen 1996; Parker & Olsen 1995). The authors also highlight a failure to identify the social conditions and family dynamics which lead some children to undertake a greater number of caring responsibilities.

Resilience

A further challenge to the research generated in the name of young carers is the absence of emphasis on notions of resilience and competence of children and young people in the context of providing care to a relative with a chronic illness or disability. Rutter (1987) describes resilience as “the positive pole of individual variations in people’s response to stress and adversity.” The research literature suggests that protective factors for children at high risk fall into three interrelated domains:

- Personal characteristics
- Family characteristics
- Characteristics of the individual’s wider social environment and external support system

Reflecting an emphasis on these domains, in their account of children growing up with parents who have learning difficulties, Booth & Booth (1998) identified factors which were associated with resilience:

- Personal protective factors ➔ individual characteristics such as being outspoken, independent-minded and ambitious
- Protective mechanism within the family ➔ warmth and mutuality, stability and security often represented as having a supportive extended family network
- Protective social supports ➔ friendships and helpful neighbours and participation and involvement in a close community

Consideration of the needs of young carers and approaches to responding to these needs are likely to be enhanced by taking account of the possible moderating influences of these factors on the lives of children and young people who take on a caring role. A further consideration is the ability of the cared-for parent to effectively maintain their role as parent. Challenges to some of the assumptions made about parenting in the context of illness and disability are presented below.

Assumptions about disability, illness and parenting

Keith & Morris (1995) argue that central to much of the research on young carers, and more generally on parents with a disability, is an assumption of inadequacy with regard to the parenting abilities of parents with an illness or disability. Olsen & Wates (2003, pp. 8) express this misconception as follows:

“Much of the research into disabled people’s parenting is steeped in a model which regards disability as a personal characteristic and links any presenting problems to individual impairments, mental health status or learning difficulty rather than with the social context and environment in which parenting takes place.”

The authors go on to state that “within this tradition, impairment is seen as the paramount variable, outcomes for children are the focus of examination and interventions to protect children from the adverse impact of parental disability are the proposed solution”. Empirical studies support this view that context is a powerful influence on outcomes. Brandt & Weinert (1998) studied 174 families recruited through the US Multiple Sclerosis (MS) Society.

Findings indicated that children were most at risk of developing mental health related problems where parental MS was accompanied by marital disagreement and a lack of financial resources. Yet despite these findings, recommendations targeted support at the children in these families without considering the financial and other support which parents and children would benefit from. Olsen & Wates (2003) conclude that researchers identify associations between impairment and poor parenting without adequately considering the role of poverty, inaccessible housing and other aspects of material disadvantage. In their view, when the socio-economic context is controlled for, differences usually attributed to impairment are not apparent.

This chapter has focused on definitions of young carers and on the differing theoretical perspectives which frame our understanding of and response to the issue of young carers. A review of these perspectives reveals a broadening of conceptual focus from earlier perspectives which concentrated on largely negative outcomes and consequences for children living with chronic illness or disability to models which highlight consideration of contextual factors such as poverty and disadvantage, the quality of family relationships and the competence of children as social agents. Reinforcing the need to be inclusive in our response to the issue of young caring, challenges to the young carers' literature draw attention to its lack of emphasis on children's resilience and the potential for positive outcomes for children who take on caring roles. These challenges remind us of the importance of remaining focused on processes rather than outcomes – of understanding what exactly are the processes which contribute to positive or negative effects on children who provide care in the family. Finally, challenges to the young carers' literature have identified the necessity of understanding not only the nature and extent to which children and young people provide care but also the impact of caring on the lives of young people.

In Summary

- A review of the literature on young carers highlights the need to be inclusive in our approach to the many theoretical perspectives on disability and illness which inform our response to young carers.
- A vast body of literature on young carers has emerged in the last decade, much of which has been generated through the efforts of the Loughborough University Research Group.
- The complexity of circumstances surrounding the role of young carers contributes to difficulties in generating satisfactory and appropriate definitions.
- Lack of clarity in defining the role of young carer leads to consequent difficulties in determining the prevalence of young carers.
- The literature on young carers reflects a shift in theoretical perspectives. Earlier perspectives tended to pathologise the family member with an illness or disability. This is in contrast to more recent approaches which conceptualise an understanding of the young carer in the context of the whole family.
- One of the key debates to emerge in the area of young carers is how to strike a balance between the rights of ill or disabled people and the rights of children who care.
- The disability rights perspective focuses on the needs and rights of disabled people. The work of the Young Carers Research Group has emphasised the need to acknowledge the rights of young carers as children and as carers, without undermining the rights of the ill or disabled parent.
- Challenges to the young carers research highlight an exclusive focus on negative outcomes for children who take on caring roles, an absence of emphasis on the resilience of children and young people in caring roles, exclusion of a focus on the ill or disabled individual, lack of robust data exemplifying the impact of caring on children and young people and absence of differentiation between the contexts of caring and their consequences.
- Challenges to the young carers research also point out misconceptions about inadequate parenting skills of parents with an illness or a disability. Such misconceptions are exacerbated by an absence of emphasis on the social context in which caring is provided.

Chapter Three: The Impact of Caring Roles on Children and Young People

Introduction

One of the key concerns in the literature on young carers is understanding the impact which taking on a caring role has on the lives of children and young people. Some degree of caring in childhood is both routine and to be valued and encouraged as part of healthy child development (Aldridge & Becker, 1998). Children and young people may take on care-giving roles in the family as a consequence of long-term or short-term parental illness or disability. These roles may be ongoing if parents do not receive the support to which they are entitled, and if professionals fail to address the needs of children in this context. The context in which children provide care also exerts a powerful influence on the consequences of the caring role for children and young people. Dearden & Becker (2002) point out that where support services and family income are adequate, children will not usually adopt a caring role. However, many families lack the necessary resources – financial and practical – to enable disabled or ill people to remain independent and to prevent children from caring. Other important factors are the nature of the illness or disability of the relative, family structure, age and gender, and the number of children ‘available’ to care within the family.

The primary focus of this chapter is on the impact of the caring role on children and young people. The chapter begins by outlining some of the primary contexts of caring and the factors which influence young people in taking on the role of carer. The chapter then moves on to consider some of the characteristics associated with young caring people. Finally, the impact of caring on young people – physical, social, emotional, and educational – is outlined and discussed.

Classification of young caring

The experiences and needs of young carers are likely to vary according to the contexts in which care is being provided. According to Frank (1995) and Banks *et al.* (2002) levels of caring provided by children can be broadly classified under the following three headings:

- **Sole carer**
A child or young person who is the only person in the household with a caring role, as no adult is available
- **Supportive carer**
A child or young person who assists an able adult who is the main carer
- **Sibling carer**
A child or young person who helps look after a disabled sibling

Factors influencing becoming a young carer

The nature of the illness or disability of family members requiring support dictates to a large extent the type and level of care provided by carers, adults and children. Thus family members with a serious physical disability or chronic illness are more likely to need practical, physical support, sometimes including personal, intimate care. Those with mental health problems may also require practical assistance but are much more likely to need emotional support and encouragement (Dearden & Becker, 1998; Aldridge & Becker, 2003).

Family structure is also very important in influencing whether children become young carers and the extent to which they are involved in care provision. Research suggests that most young carers live alone in lone-parent families where there is only one adult, usually though not always a mother (Dearden & Becker, 1998). If a lone parent becomes ill and requires support there is no adult partner and caring often falls to children within the family. This does not mean, however,

that in two-parent families children do not become carers. In some cases the other adult in the home will continue in paid employment to provide the family with an income, and in other families an adult will choose not to become a carer. In a survey of 2,303 young carers carried out in 1998 in the UK, 54% of young carers were living in lone-parent families. Overall the majority (58%) of all care recipients were mothers and this was especially so in lone-parent families where 76% were mothers (Dearden & Becker, 1998).

In families where there is more than one child, care may be shared or one particular child may become the carer. Age can be a significant determinant in some families, with older children carrying out most of the caring tasks. Nevertheless, younger children may learn to do more as they grow older and may become more involved when their older siblings are socialising and perhaps leaving the family home. Dearden & Becker (1998) found that the likelihood of involvement in most caring tasks increased with age. They also found that girls were more involved in all aspects of care and that this was especially marked in relation to domestic chores and intimate caring tasks.

Contexts and characteristics of young carers

According to Banks *et al.* (2002), the relationship between the young person providing care and the person they are caring for may be influenced by the context in which care is being provided. A number of reasons have been identified for why a young person, rather than an adult, may take on primary caring responsibilities. Thomas *et al.* (2003) summarise these reasons. First of all, young people take on caring roles when both parents are ill or disabled (Frank, 1995) or due to the absence or death of one parent coinciding with illness or disability in the other (Aldridge & Becker, 1993a). In other circumstances, children take on a caring role as the parent who is not ill or disabled may have to go out to work (Frank, 1995) or because other members of the family make themselves unavailable (Aldridge & Becker, 1993a). Children may also be caring for a parent with a mental health problem or a dependency on alcohol or drugs. In other circumstances, children may be providing care for a sibling with an illness or disability or an extended family member, as for example, an elderly grandparent who is frail or who has a health problem or disability.

Research by Carers Association of South Australia (2003) indicates that young people almost always live with the person they care for and are most likely to be caring for a parent, especially their mother. Many live in lone-parent households and many are providing care within the context of low-income families or other circumstances of disadvantage. Primary care responsibilities are more likely to be carried out by girls than by boys. Approximately half of young carers in Australia provide care for someone with a physical disability and at least a quarter support a family member with a mental illness. According to this report, despite their age, these children and young people carry out the same range of emotional and practical care activities as adult carers and spend much of their time providing care, and worrying or thinking about the person they care for.

Booth and Booth (1997) suggest that children take on caring responsibilities when the family is inadequately supported by State agencies or the family and community. Frank (1995) points out that the able parent may become depressed because of their inability to cope with their partner's condition and the lack of appropriate support. Consequently, the burden of responsibility may then fall upon the children. It is clear that several of these factors are likely to vary with socio-economic conditions.

Children and young people who take on care-giving roles carry out a range of tasks in the home. These tasks include household tasks and personal, social and emotional caring responsibilities (Meredith, 1991; Frank, 1995; Mahon & Higgins, 1995). Earlier quantitative studies provided valuable information regarding the extent to which children and young people were involved in providing primary care to a parent or relative. However, quantitative studies were limited in that they provided little insight into the specific nature and impact of children's caring roles (Page, 1988; O'Neill, 1988). More recently, qualitative studies have enabled us to gain greater insight and understanding into the daily lived experience of caring and of alterations to the roles and responsibilities of children and young people providing care in the context of family.

Caring tasks and responsibilities of young carers

The impact of caring on children and young people's lives is likely to be closely linked to the nature of the tasks that they are engaged in. As mentioned previously, Dearden & Becker (1998) carried out a large scale survey involving 2,303 young carers in the UK. Young people who participated in this study were found to be involved in a range of care-giving tasks including domestic tasks (72%), general care such as assisting with mobility or giving medication (57%), emotional support (43%), intimate care (21%) and child care for siblings (7%). Children were found to be performing a range of tasks from basic domestic duties such as cleaning, cooking, etc. to very personal, intimate care such as bathing and toileting. While the children demonstrated a commitment to performing these tasks as a means of supporting family members, no children were comfortable with providing intimate care. Table 3.1 below shows the incidence of different caring tasks in 1995 and 1997 surveys of young carers around the UK (Dearden & Becker, 1995, 1998).

Table 3.1. Caring tasks and responsibilities of young carers

Caring Tasks	1995	1997
Domestic	65%	72%
General	61%	57%
Emotional Support	25%	43%
Intimate Care	23%	21%
Child Care	11%	7%
Other	10%	29%

Source: Dearden & Becker (1995, 1998)

The impact of parental illness and disability on children's lives

Previous research has identified a number of ways in which the caring role may have an impact on the lives of children and young people (Thomas *et al.*, 2003; Meredith, 1991; Becker *et al.*, 1998). These have typically been summarised under headings as follows: physical impact, emotional and psychological impact, social impact, educational impact and young carers' future adult life. Findings across a range of studies are discussed under these headings in the sections below.

Physical impact of parental illness and disability on children's lives

Qualitative studies of young carers have drawn attention to the possible implications of caring for children's own health (Bibby & Becker, 2000; Hill, 1999). Lifting a sick or disabled person can lead to back strain and the increased likelihood of back problems in adulthood (Hill, 1999). However, social workers and community nurses do not feel that this is an appropriate task for a child and, therefore, children are not taught to lift adults in a safe manner. In addition to the demands of physical care tasks, poor physical health for young carers can also arise from increased stress and limited sleep associated with the role of caring for an adult in the family (Carers Association of South Australia, 2003). In a recent analysis of the health status of young and elderly informal carers in the UK, findings indicated that the health status of many children under 16 providing 20 or more hours of care was evaluated as "not good" (Doran, Drever & Whitehead, 2003).

Emotional and psychological impact of parental illness and disability on children's lives

Much of the research linking parental illness and disability with children's caring roles highlights the emotional and psychological impact on children's lives. Frank (1995) identified feelings of resentment and a sense of isolation experienced by young carers. In a study commissioned by the National Assembly for Wales as part of a wider review of carers' needs and services, findings indicated that most of the children and young people interviewed experienced feelings of sadness, anxiety and difficulties with friendship and family relationships (Thomas *et al.*, 2003). Additional stressors included worry and anxiety associated with caring for somebody else and a lack of recognition of the role of the young

carer by the outside world. Children and young people worried about the person they were caring for in terms of the safety and well-being of this person. Children also worried about the possibility that they themselves might be separated from the cared-for person as, for instance, where there was a possibility of their being taken into care.

Cree (2003) argues that mental health has a special significance for young carers as children and young people in a caring role may have acquired very negative ideas about what constitutes mental health and mental illness and may, consequently, be reluctant to admit that they themselves are suffering from anxiety. In a study of young carers in Scotland involving 61 children and young people, the author identifies three categories of young carer according to the significance and severity of problems and worries expressed. The first group involved young carers who had problems and worries which are typical of adolescent concerns (e.g. worries about body image, friendships, relationships with parents, schoolwork etc.). A second category of young carer worried a great deal about caring and the person for whom they were caring in addition to the typical problems and concerns experienced by teenagers. Finally, and of more immediate concern was a third category of young carer who had had (or were experiencing) major disruption and loss in their lives (including family violence, sexual abuse and homelessness), in addition to typical adolescent problems and their worries about caring and the person they were caring for. The evidence provided by this study is that being a young carer may put additional pressures on children and young people at a time in their lives which is already stressful. Findings also indicated that older young people and girls involved in caring expressed more problems and worries in relation to their well-being, suggesting that they may have particular needs that should be addressed. In addition, both problems and worries increased with the length of time spent being a young carer.

Social impact of parental illness and disability on children's lives

Within families it is often one child who is chosen to take on the caring role by other family members. Dearden & Becker (2000) argue that once the role of caring becomes established, the child or young person is socialised into this role, perceiving it as natural and becoming unable to envisage alternatives. Opportunities for contact with peers can also be negatively affected where children are providing care. Caring responsibilities can lead to a lack of opportunities for socialising with peers and for participation in sporting and leisure activities, which, in turn, can result in social exclusion (Aldridge & Becker, 1993b). Frank (1995) found that many young carers seemed to be isolated from their peers.

Educational impact of parental illness and disability on children's lives

At least a quarter and probably one third of young carers in the UK experience difficulties with school attendance and academic achievement (Dearden & Becker, 2002). In addition, young carers are more likely to miss out on out-of-school educational opportunities such as after school clubs, visits and holiday programmes (Tatum, 1999). One of the first studies to focus on young carers and education was conducted in the London Borough of Enfield (Marsden, 1995). In contrast to most recent studies, this study did not include children and young carers directly in the research process but obtained information from professionals in education and other services. The major educational difficulties identified were punctuality, attendance and problems with homework and coursework. Extra-curricular activities were also negatively affected with young carers experiencing difficulties in participating in these activities. Young carers were also found to have difficulties with social integration and peer-group activities, which in turn was considered to have a major impact on young people's educational experience. Related problems included low achievement, anxiety and fatigue (Marsden, 1995). According to this study, teachers indicated that they would find it helpful to have a detailed list of services and contacts which could assist both the young carer and the care recipient.

It is not possible to assume cause and effect in poorer educational outcomes for children as carers as we do not know whether young carers are any more likely than any other group of vulnerable children to experience educational disadvantage as a direct consequence of their specific status. In many cases, caring may be only one element in a configuration of stressors such as poverty, isolation and social exclusion.

However, qualitative interviews with young carers provide us with some insight into the daily concerns which may represent barriers to attendance and progress at school and may contribute in this way to poorer educational outcomes for young carers. In one such study, children reported feelings of anxiety about their ill or disabled relative which they perceived to be an obstacle to concentration (Dearden & Becker, 1995). A nationwide study in England, involving 60 young people between the ages of 16 and 25 who were either caring at the time of interview or had cared during their childhood for a parent with a long-term illness or a disability found that half of the sample had missed some school and a quarter had no GCSEs⁵ (General Certificate in Secondary Education) (Dearden & Becker, 2000a). The majority of these young people indicated that missing schooling was related to their caring roles. Reasons included reluctance to leave ill parents alone or, in a small number of cases, because parents did not want them to go to school. In more extreme situations, absence from school is associated with the nature of the illness as in the case of children whose parents have a history of self-harm or suicide (Aldridge & Becker, 2003).

Underdown (2002) highlights the need for greater awareness of the particular difficulties experienced by young carers among teachers and other staff members in schools. Many young carers indicated that schools lacked sufficient understanding of their situation. Children and young people expressed feelings of being stigmatised and isolated in the context of school and labelled as 'problem-children' if they were unable to complete homework due to caring commitments. Longer-term consequences of educational disadvantage as a result of caring during childhood may include reduced career choices and opportunities.

Future adult life of young carers

The responsibility of providing care to a family member as a child or young person may also have an impact on future adult life. The boundaries between childhood and different aspects of adulthood are often blurred and indistinct. Booth & Booth (1998) argue that when discussing issues related to children growing up with parental disability and illness, it may be more appropriate to think of a range of transitions to a variety of different 'adulthoods'. The authors present findings from a study of 30 adults who had grown up with parental learning disabilities. Transition to adulthood was discussed under several focal aspects as defined by Morrow & Richards (1996). These aspects included leaving school, leaving home, forming intimate relationships and the transition to parenthood. Findings suggest that in establishing an adult status for themselves in society, participants in the study experienced no greater problems than other people coming from the same socio-economic background.

According to young people involved in looking after a family member, caring can have both positive and negative impacts on their lives as they grow into adulthood (Dearden & Becker, 2000a). In a study involving 60 young people aged between 16 and 25, the positive and negative aspects of caring were outlined. Positive impacts included earlier maturity, learning to take responsibility, developing life-skills and a close, loving relationship with parents. Negative impacts included stress and sometimes depression, restricted social, educational and career opportunities and impaired psycho-social development.

Transitions from school to employment were complex. Previous absence from school and poor educational qualifications put many of the participants at a disadvantage in the labour market. Despite the evidence of educational difficulties, many young people continued into further education. However, Dearden & Becker (2000a) argue that this was as much due to the absence of any suitable alternative as other reasons. Difficulties were compounded in adulthood by the fact that many young carers found it difficult to take on part-time work while they were studying. Only a quarter of the sample was in full-time paid employment. With regard to the transition of leaving home, findings indicate that caring can lead to young people having to leave home earlier or later than they would typically choose. Many carers reaching adulthood felt they could not leave the family home as their parents depended on them for support.

⁵ Roughly equivalent to Junior Certificate in the Irish educational system

The researchers conclude that children and young people who adopt inappropriate caring responsibilities can be affected not only during childhood but also as they become adults. The absence of family-focused, positive and supportive interventions by professionals, combined with inadequate income, have negative effects on young people as they move from adolescence into adulthood. However, the authors underline the fact that parental illness or disability is usually an indirect influence on outcomes for the young carer. Direct influences are more likely to be appropriate and affordable social care services, educational difficulties, poverty, social exclusion and stress.

Parentification

Parentification has been described as the expectation that one or more children will fulfil the parental role in the family system (Boszormenyi-Nagy & Spark, 1973). The child may act as parent to other children in the family or may be expected to care for the parent (role-reversal) or both. Such care arises in the contexts of parents having an emotional, physical or intellectual impairment or a combination of these. Practical difficulties such as providing physical care for a parent combined with less concrete difficulties such as experiencing fears about the future, fears of contracting the same illness, limited access to a social life and opportunities to develop relationships outside the family may all take their toll on the child's life.

Responsiveness to parental need is not inherently problematic and may help children develop sensitivities and reciprocity with others (Chase, 1999). Parentification becomes problematic, however, when there is "a lack of acknowledgement and reciprocity between adults and children in terms of the nurturance exchanged or when expectations, either emotional or logistical, exceed the child's abilities, damage well-being and ignore the child's developmentally appropriate needs." Jurkovic (1997) delineates four categories of roles on a continuum of responsibility according to duration and extensiveness of care-taking. Extreme over-functioning is labelled as 'destructive parentification' and extreme under-functioning is 'infantilisation'. In the middle range are 'healthy non-parentification' and 'adaptive parentification'. These two categories entail some appropriate responsibility for the child. In the 'adaptive' category, care-taking responsibility may increase or intensify because of crisis or acute stress, but such contribution by the child is recognised and expected for a limited time only. The parentified child status has been studied across a number of contexts including children of parents with schizophrenia and children of divorced or separated parents.

Central to an understanding of the impact of caring on children and young people is an understanding of the nature of the relationship between the carer and the person with a disability (Nolan, Lundh, Grant & Keady, 2003). Nolan *et al.* (2003) highlight the fact that there are increasing calls for consideration of relationships to be a core component of any assessment of the need for help and support for carers (Nunley, Ball & Rowles, 2000; Snyder, 2000). The authors also highlight the importance of a strengths-based approach to work with family carers (Berg-Weger, Rubio & Tebb, 2001). A strengths-based model acknowledges both the difficulties and rewards of caring but seeks to build primarily on the latter. Such a model also encourages carers to consider the many and varied forms of competence which they possess. Berg-Weger *et al.* (2001) stress the need to develop a more extensive range of strengths-based assessment tools to help introduce such a way of working to routine practice and to contribute to the design and development of more meaningful support for family carers and disabled people.

Children caring for parents with mental illness

A summary of information from UK statistics suggests that about 30% of mentally ill parents have dependent children. It has been suggested that a significant proportion of children living with a mentally ill parent will develop psychological problems or disorders (Falkov, 1998). Research by Quinton & Rutter (1984) found that over a four-year period, one third of the children of consecutive new psychiatric patients showed a persistent disorder, one third had transient difficulties and one third did not show any emotional or behavioural problems. The most frequent problems presented by the children were behavioural problems. However, it was not the presence of parental mental illness *per se* which explained the presence of difficulties. Psycho-social factors associated with psychiatric patients, such as the greater prevalence of lone-parenting, parental separation and marital conflict, were identified as contributing to more negative outcomes.

The effects of parental mental illness on the development of the child may be direct as, for example, where children witness the delusions, hallucinations and obsessions of their parents. However, Barnes & Stein (2000) argue that much more frequently it is the parents' preoccupation and unavailability that is likely to be more damaging. Where a parent is depressed the impact on a child's development may be greater. Children of depressed parents have not only a three-fold greater risk of major depression but also show a similar increased incidence of phobias, panic attacks, alcohol dependence and social problems. These children may also manifest an increase in behaviour problems and substance abuse.

By contrast, others have asserted that many children show no long-term behavioural or emotional disorder when parents have a mental illness. Central to children's well-being is ease of access to support, both in terms of informal support from family members and friends and more formal support services, if and when problems do occur (Cleaver, Unell & Aldgate, 1999). Aldridge & Becker (2003) highlight the importance of acknowledging that despite the often difficult and 'different' lives of young carers as well as the negative consequences of other factors, most young carers of parents with mental illness reported having positive relationships with their parents. However, it is very probable that security in the child-parent relationship in the context of parental illness – and especially in cases of severe and enduring mental health problems – can be undermined by the symptomatic outcomes and behaviours of parents. The authors identify factors potentiating negative outcomes as follows: inadequate or ineffective external support for parents, discontinuity in child-parent relationships as a result of hospital admissions or child protection procedures, fear of discriminatory professional interventions and coping with multiple challenges such as a range of physical and mental health problems coupled with social problems such as poverty, low income and social exclusion.

Children caring for siblings

Research has also examined the role of siblings as care-givers in the context of children with a chronic illness or disability (Stoneman, Brody, Davis & Crapps, 1987, 1989; Brody, Stoneman, Davis & Crapps, 1991). Findings indicate that older sisters of children with disabilities had significantly more responsibility in tasks such as personal assistance, adaptive tasks, meal preparation and babysitting. Research also indicates that siblings of children with disabilities are more involved in care-giving and household tasks, with care-giving being related to greater sibling anxiety (McHale & Gamble, 1989). In many cases, children experience a mix of positive and negative feelings so that ambivalence is a common feature of sibling relationships (Banks *et al.*, 2001). Children with a disabled sibling may experience more anxiety although this is dependent upon their understanding of the condition or disability (Summers, 1994; Roeyers & Mycke, 1995). Studies have also shown that siblings of children with disabilities spend significantly less time in school (Boyce, Barnett & Miller, 1991).

Problematic outcomes for children are most frequent when parents of children with a disability or disease are overwhelmed by their parenting roles (Chase, 1999). Under these circumstances it is possible that the roles and identities of siblings begin to expand beyond their usual limits, which may increase the risk of dysfunctional parentification of siblings. Problems arise where excessive parental attention is focused on the child with a disability or chronic illness at the expense of focusing attention on a sibling. Under these circumstances, some siblings may learn to assume the role of the 'little helper' or the 'little parent'.

Protective factors have been identified that can support siblings who are providing support to a sibling with an illness or disability. According to Jurkovic (1997), roles and responsibilities characterised by developmental appropriateness for these siblings, clear definitions and supervision of assigned tasks, and the distribution of responsibilities throughout the family, can be important balancing factors (Minuchin, 1974).

Young carers from minority groups

The UK National Strategy on Carers (H.M. Government, 1999) highlights the particular case of young carers from ethnic minority groups who, in addition to sharing the specific experiences of all young carers, also face additional challenges. Families from minority groups may be less likely to contact social service departments for fear that their children will be taken away. Children from ethnic groups are also more likely to be excluded from school. The Strategy points out that

action is already being taken through initiatives to reduce school exclusion and through behaviour support plans to combat such problems. An additional stressor for children in families from minority groups is that they may often find themselves having to take responsibility for interpreting for the person that they are caring for, regardless of whether or not they understand the issue and whether it is appropriate to their age.

In a collaborative study between the Manchester Metropolitan University and the Bibini Centre for Young People, aimed at investigating the experiences, needs and access to services of black young carers and their families, a number of issues were highlighted (Jones, Jeyasingham & Rajasooriya, 2002). First of all, the term 'young carer' had limited value for the children and families in this study and was not a term that most of the children and young people in the study identified with. Categorising children and young people as 'young carers' ignored the complexity of caring roles within family life and risked masking or perpetuating the social inequality experienced by the whole family. Secondly, the research highlighted the failure of agencies to provide adequate support to young black people with caring responsibilities. It also indicated a high level of unmet social, personal and in some cases, medical care needs among black parents (and other family members) who are disabled or experience ill health. Thirdly, there was a lack of understanding among social services, healthcare professionals and schools of the problems families faced and there were examples of discrimination by race and/or disability. Fourthly, where parents did not speak English, children were often required to act as interpreters. This was not always appropriate, especially if the child was very young or if the information was of a complex or sensitive nature.

This chapter has outlined some of the factors and consequences associated with children and young people taking on the role of carer. Key factors identified include the nature of the disability or illness, family income and access to support services. A number of different caring contexts and tasks were also outlined. Understanding and responding to the needs of young carers requires an acknowledgement of the potential impacts which caring roles exert on the lives of those who undertake them. Developing appropriate and effective service and policy responses demands consideration of the potential implications of young caring for the lives of young people.

In Summary

- Key factors identified as contributing to young people taking on the role of carer include the nature of the illness or disability within the family, family income and support services available, family structure, and age and gender of children.
- Young caring often involves carrying out a range of tasks including household tasks and personal, social and emotional caring responsibilities.
- The impact of caring on children and young people is most typically discussed within the context of the physical, social, emotional and educational development of young people. Caring has further implications for the adult life of the young carer.
- Physical effects include back strain due to lifting or physically assisting parents, limited sleep due to caring responsibilities and anxiety and the effects of stress on the physical health of the young person.
- Emotional and psychological effects include feelings of sadness and anxiety, fear of separation from the cared-for parent, and stresses associated with caring for a parent with a mental health problem.
- Social effects include restricted or absent opportunities for socialising with peers and for engaging in sporting and leisure activities.
- Approximately one quarter and probably one third of young carers in the UK experience negative effects on their education. Educational difficulties include problems with punctuality, attendance and difficulties with homework and coursework. Lack of awareness by teachers and other educational professionals of the specific circumstances of young carers may exacerbate these problems.
- Opportunities for career development and future employment in adulthood are often negatively affected by the knock-on effects of restricted educational achievement. Other negative effects reported in adulthood include depression and impaired psycho-social development.
- Central to an understanding of the impact of caring on children and young people is an understanding of the nature of the relationship between the carer and the disabled person.
- Findings are mixed regarding the well-being of children and young people caring for a parent with mental illness. An important consideration in the well-being of these children is ease of access to support, both in terms of informal support from family members and friends and more formal support services, if and when problems do occur.
- Young carers from ethnic minority groups, in addition to sharing the specific experiences of all young carers, also face additional challenges, such as their families' reluctance to make contact with social service departments, experiences of discrimination by race and the responsibility to act as an interpreter for parents which may involve communicating information of a complex or sensitive nature.

Chapter Four: Service and Policy Responses to Young Carers Abroad

Growing awareness and recognition of the experiences of young carers in the UK is reflected in greater commitment to the development of service and policy initiatives. As outlined in previous chapters, however, a number of dilemmas combine to obscure recognition and awareness of the needs and appropriate responses to young carers. The validity of identifying young carers as a distinct category for targeted support has been questioned by those arguing mainly from a disability rights perspective. In addition, there are inherent contradictions within policy and law concerned with promoting care in the community, supporting disabled people and protecting children (Becker, Aldridge & Dearden, 1998). The complexity of developing appropriate policy and service responses to support young carers is added to by uncertainty regarding whether this support should be provided through specialised services for children or more general community care services. In addition, the notion of young carer is considered by some to represent a challenge to the view of childhood as a special phase where children's welfare is promoted and supported through upbringing within the family. The following sections provide a brief overview of policy and service developments abroad, with particular reference to the UK, Australia and the rest of Europe.

Service and policy responses to young carers in the UK

Key policy and legislative changes

The Disabled Person's Act, 1986 was the first piece of legislation in the UK to mention carers. It established that any assessment of a disabled person must take into account the carer's ability to continue providing the care (Clements, 1995; Watson, 1999). A second piece of legislation The Children Act 1989 also has relevance indirectly for the well-being of young carers. (Section 17 of this Act relates to children deemed to be 'in need'). As children taking on responsibilities that could be detrimental to their own health and development, young carers fall into this category (Watson, 1999). Measures to support children must take account of the possibility of keeping the family together and could, therefore, take the form of care or assistance for a parent or a sibling, rather than direct assistance for the child in need (Heal, 1995; Watson, 1999).

The first report by the Department of Health in the UK to address the issue of young carers was published in 1995. In *Young Carers: Something to Think About* (SSI, 1995), a number of policy issues were addressed. Firstly, questions concerning the definition and identification of young carers were dealt with. The importance of developing support responses which provide an appropriate focus on the child's needs was also emphasised. Related to this, a 'whole family' approach which emphasises the need for adequate services for ill or disabled parents was also highlighted. Finally, integrated responses among different agencies were strongly advocated.

Aldridge and Becker (2003) highlight a number of key changes in policy and legislation in the UK over the last ten years, which have direct relevance for young carers. These include the Carers (Recognition and Services) Act 1995 implemented in April 1996, which gives carers of any age – including young carers – the right to an assessment of "their ability to provide and to continue to provide care". In practice, this may be difficult to implement as social workers or community nurses cannot always interview a carer separately from the person they are caring for (Becker, 1995; Watson, 1999). A carer may feel unable to express reluctance to continue caring, for fear of being considered as selfish or indifferent.

In 1999, the UK National Carers Strategy, *Caring about Carers* (H.M. Government, 1999) committed the government to a number of initiatives to improve the situation and support of all carers. In a separate chapter on young carers, specific recommendations were made in response to problems of identification, the development of specific services such as respite care and counselling services and promoting greater awareness and training opportunities for professionals. The need for specific support to young carers who were providing regular and substantial care for those with severe mental

illness was also highlighted. Finally, the Carers and Disabled Children Act 2000 gives carers over the age of 16 years (and caring for someone over the age of 18) new rights. These rights include being able to request an assessment of their own needs even in situations where the person receiving care does not wish to have an assessment. Frank (2002) advocates direct local consultation with children, young people and their families as part of the process of developing support services for young carers.

Assessment and services for young carers in Scotland and the UK

In a review of the literature on assessment and services for young carers in Scotland and the UK, commissioned by the Scottish Executive, a number of issues were highlighted (Banks *et al.*, 2002). Some of these issues are summarised under the following headings: identification processes, needs assessment and service approaches.

Identification processes

A number of complexities involved in identifying young carers were outlined. A key difficulty identified was the fact that the term 'young carer' is not one that originates from children or young people involved in the process of caring themselves. In fact, evidence indicates that most young people involved in caring do not like the term or identity of 'young carer' (Banks *et al.*, 2002). Children and their parents are often unwilling to seek help for a variety of reasons, including a wish for privacy, feelings of stigma and fears about community or professional responses. There is little knowledge of how young carers, therefore, come to the notice of local authorities. Access to young carers' projects is usually facilitated through social workers, health professionals and teachers. Once these projects have been established, the majority receive self-referrals and referrals by parents.

Needs assessment

Banks *et al.* (2002) underlined four main needs of young carers identified in the literature as follows: (i) ease of access to information about parental well-being, available services, etc.; (ii) access to individual support or counselling; (iii) the availability of practical assistance where needed and (iv) access to social contacts and recreation. In contrast to this, the disability rights perspective emphasises that the main need of young carers is to prevent or eliminate young caring by means of financial and practical support to the whole family. In general, however, all stakeholders would agree that the needs of the whole family must be taken into account in attempts to respond to the problem of young carers. Consequently, frameworks which promote a more holistic approach to assessment have been advocated for use by statutory and voluntary agencies. These frameworks promote integrated attention to the child and to broader contextual factors such as parenting capacity and the wider environment.

The *Framework for the Assessment of Children in Need and their Families*, produced and promoted by the Department of Health (2000), has been applied to young carers and their families in the UK. This is based on research findings about parent-child relationships, child development and risk/protective factors. Although the primary focus is on within-family circumstances, it views the needs of the young carer from an ecological perspective. Attention is given to external environmental influences and the part played by service agencies, individually and collectively. The framework covers three particular domains of experience: the child's developmental needs, parenting capacity and family and environmental factors.

Dearden & Becker (2000b) incorporate these domains into their approach to the assessment of the needs of young carers. With regard to the developmental needs of young carers, the authors point out that young carers may have additional needs including educational difficulties, feelings of isolation and being different and lack of time for recreation. In the second domain of parenting capacity, they point out that this is closely related to the nature of the parents' illness or disability in that parental mobility and strength may be affected. However, they stress the importance of highlighting parental strengths as well as challenges to parenting. Finally, in the third domain of family and environmental factors, problems such as low income and inadequate housing coupled with prejudice and discrimination may contribute to creating additional stressors for young carers and their families.

Service approaches

Banks *et al.* (2002) describe a shift in emphasis in terms of services to support young carers. Earlier approaches adopted the stance that support should be provided to children and young people independently of their families. However, as previously outlined, more recent approaches advocate a more integrated 'whole family' approach which underscores the need to provide assistance, not alone to the young people in caring roles, but also to all family members and to the parent living with an illness or disability.

Young carer projects

One of the most well-known methods of providing support to young carers in the UK has been through the establishment of young carer projects, the majority of which are provided by voluntary organisations. Young carer projects became established in the early 1990s as a means of addressing some of the problems identified by research into young carers' experiences (Dearden & Becker, 2002). At present, there are about 110 young carers' projects in the UK (H.M. Government, 1999). Many of these projects are run on a once-off basis and have been developed to meet local needs. However, most are run by larger organisations concerned with children, disability or mental health. Projects typically provide three kinds of intervention:

- Group activities and discussions
- Individual counselling
- Befriending and advocacy on behalf of the child or family

A number of differing views have been expressed regarding the value of young carer projects. Attitudes vary with regard to whether devoting resources to young carer projects is a necessary response to what is perceived as a shortfall in support to adults or whether these projects contribute to that deficiency by diverting attention and money (Banks *et al.*, 2002.). In response to this critique, Dearden & Becker (2002) point out that young carer projects are becoming increasingly 'family-focused' and work towards assisting disabled parents in meeting the needs of their children rather than supporting these children and young people independently of their families. Other views acknowledge that the projects can provide relief from the isolation faced by children and young people in the role of carer through the provision of advice, information and support or leisure activities (Frank, 2002).

While evaluations of individual young carers' projects have been carried out at local or regional level, there does not appear to have been an evaluation of these projects nationwide to date. Three projects, Nottingham Young Carers Project, Capital Young Carers Project (Southwark) and Sheffield Young Carers Project were evaluated by researchers from the Centre for Child and Family Research (CCFR) during the 1990s and early 2000s, against a framework of their own stated aims and objectives. These projects were found to have achieved most of their aims and objectives and were highly valued by young carers, their parents and professionals from a range of organisations and agencies, such as health, social services and education welfare services, who referred children to the projects (Dearden & Becker, 2002). The projects also worked closely with the families of young carers and this family-centred approach ensured that parents did not feel undermined by the work of the project. The young carers' projects were often a source of information and advice for parents when they had a problem relating to their own care needs. Social and leisure activities were valued most by the young carers. One of the most important achievements of the projects was the way in which they validated young carers' experiences – introducing them to others in similar situations and allowing them to openly discuss something that many had kept hidden from peers. Aldridge & Becker (2003) suggest that young carers' projects are highly valued by young carers and their families as well as by statutory welfare professionals (SSI, 1996; Aldridge & Becker, 1998; Becker *et al.*, 1998).

Banks *et al.* (2002) indicate that much less information is available about the nature of local authority and health service provision. The authors conclude their review by pointing out that services for young carers are a prime example of the need for concerted efforts by different agencies and professions to develop a shared approach and to provide coherent services based on holistic assessments. They highlight the need for a well co-ordinated programme of interventions aimed at reducing the need for children to be sole or major carers, while ensuring that children have access to separate, confidential support where this is required. The authors also point out that further research is needed in the UK to

identify more clearly the spectrum of caring responsibilities undertaken by children within families covering households with and without a parent or child who has a disability.

An intervention to support children who have parents with a mental illness has been piloted in the US with favourable accounts of its effectiveness. The *Positive Connections* programme in the US (Orel, Groves & Shannon, 2003) is available to children between the ages of 8 and 13 who have a parent with a diagnosed mental illness. The programme emphasises inter-agency collaboration and provides a direct service to children by matching adults and children in quality mentoring relationships. The primary purpose of the programme is to enhance children's ability to understand and to cope with their parents' mental illness by providing education, support and mentoring. It is through these three components that the long-term goals of the programme are met.

Findings on participants who completed the initial cycle of the *Positive Connections* programme revealed that most measures indicated improvements in levels of functioning, as, for example, in the areas of self-esteem, confidence and academic achievement. This project, therefore, identifies a new area of intervention that may enable children to feel more competent and to utilise a variety of supports in their social networks. Adapting the principles and some of the strategies incorporated in this programme, and identifying other similar innovative programmes in response to the needs of young carers, depends upon research efforts to identify and highlight high-quality, effective programme responses.

Approaches to service and policy development for young carers in Australia

Australia is one of the few other developed countries where there is some information already available on young and adult carers. As previously outlined, the 1998 Australian Bureau of Statistics Survey of Disability, Caring and Ageing reported that 388,800 young people under 26 years of age provided care for family members or friends. Half of these young people were under 18 years of age, with an average age of 12-13 years. Research on young carers in Australia has drawn together similar findings and conclusions as research in the UK and other European countries (Becker *et al*, 1998). In terms of the support needs of young carers and their families, the Australian research points out that young people tend to become involved in providing primary care to a family member in the absence of other support systems (Price, 1996). The importance of recognising that support must be provided taking into account the needs of the whole family is also reinforced by Australian research findings. The Carers Association of New South Wales has developed a programme of work for young carers and their families including an information pack for young carers and a training package for service providers and teachers.

A review of service and policy development for young carers in Australia (Carers Victoria, 2003), underscores the value of adopting a comprehensive and multi-faceted approach in order to respond to the needs of young carers and their families. Responses focused on prevention, early intervention and targeted support are considered essential. A central issue for policy and programme development in Australia is adopting a whole-of-government approach to address the key issues for young carers. In the following sections, a brief overview of some of the key issues outlined is presented.

Community awareness and capacity building

Promoting greater understanding and awareness of disability and illness and the impact of this on children with caring responsibilities was highlighted as an essential first step to be taken in order to develop effective support mechanisms for young carers. Strategies that increase recognition and knowledge of young people who have taken on the role of carer, through, for example, media coverage, community information and local community presentations and forums, were viewed as an essential means of reducing barriers for young carers seeking support.

Education of service providers and improved practice in existing service delivery

The review emphasised that existing services and professionals that support a child or adult with disability/illness were failing to identify children and young people affected by caring responsibilities. Early identification of vulnerable young people and assessment which took account of the needs of the whole family were advocated. Such an approach was viewed as possibly contributing to greater resilience and a reduced impact on children. In addition, providing information to health professionals and service providers was advocated as an essential step in order to develop appropriate information and supports based on local consultation.

Providing support through schools and tertiary institutions

As the average age of young carers in Australia was reported nationally as 12-13 years (Australian Bureau of Statistics, 1998), primary and secondary schools were viewed as being ideally placed for implementing strategies which would enhance educational participation and well-being. Specific programmes were advocated to assist young carers in balancing studies and school commitments with caring responsibilities. Similar programmes were also recommended at third level.

Recreation and youth services

One of the key difficulties for children and young people engaged in caring for a family member is the consequent lack of opportunity for contact with peers and recreational activities. The review recommended fostering greater social participation and leisure skills through mainstream programmes in the youth and community sector. Innovation, collaboration and the development of best practice approaches were viewed as critical. Commitment to ongoing government funding to sustain the support provided to these children and young people was also viewed as essential.

Transition to adulthood and employment

Young carers may be at risk of substantial disadvantage with regard to entering employment and subsequently at risk for more longer-term marginalisation and hardship. Targeting young carers under existing employment programmes was considered an effective means of facilitating their entry to and retention in the workforce. Similarly, the development of strategies to raise employer awareness and incentives to provide workplace flexibility and support were required to sustain young carers in the workforce.

Income support for young carers and their families

The need to review the adequacy of existing income support to families in care-giving circumstances was also highlighted in the review of service and policy approaches to young carers in Australia. Provision of additional concessions and assistance to families and to primary young carers was recommended as a means of ensuring a decent standard of living and full participation by young carers in educational and social opportunities.

The review concludes by underlining the need for further research and evaluation of the effectiveness of intervention approaches. In particular, the review highlights the fact that little information is available regarding the needs of different age groups and the impact of differing circumstances, including different family structures and cultural backgrounds on young carers. There is also limited evaluation and information available as to the effectiveness of intervention approaches.

Service and policy approaches to carers across Europe

Developments in service and policy responses to young carers are not so evident in other countries across Europe. Becker *et al.*, (1998) point out that despite awareness that throughout Europe the family is the foundation of care for disabled and older people, there is little recognition given to this contribution made by family carers and little support for them from statutory authorities (Jani-Le Bris, 1993). Unlike the UK, there is little available information on carers in other countries in Europe and little evidence of policies which reflect any commitment to supporting individuals taking on a caring role within the family.

Millar & Warman (1996) explored how the balance between State provision and family support, with particular reference to informal care-giving, is defined in law and policy across Europe. The authors identified four categories of approach to defining family obligations towards older or disabled relatives, reflected in laws and policies across Europe. These groups varied from those with clearly defined family obligations in legislation to those countries with clearly defined State responsibilities, with much less dependence on family provision of care. These four categories of approach are described in the following sections.

Extended family

Countries identified within this category include Italy, Spain and Portugal. Within this category the family, including extended family members, have legal obligations to provide financial support for each other with little responsibility on the part of the State for the provision of care.

Parents and children

Countries identified within this category include Austria, Belgium, France, Germany, Greece and Luxembourg. Within this category, adult children have maintenance responsibilities towards their parents. In Austria and Germany adult children have, in theory, financial obligations to pay for the care needs of their parents but recent policy has moved so as not to enforce payment but to require individuals in employment to take out care insurance.

No clear responsibilities

Countries identified within this category include Ireland and the UK. Within this category, family members have no formal legal obligations to provide or pay for the care of older people or disabled adults. The responsibilities of the State are not clearly defined either. However, local regulations in the UK have required family members in some circumstances to make financial contributions towards the care of their elderly parents.

Clear State responsibility

Countries identified within this category include Denmark, Finland, the Netherlands, Norway and Sweden. Within this category, State obligations to adults with care needs are made explicit and support is directed towards the individual with care needs. In many of these countries there is legislation giving authorities explicit duties to maintain vulnerable people in their own homes within the community.

Millar & Warman (1996) conclude that there are two extremes of approach which emerge from this analysis. The first approach is evident in southern Europe (Italy, Greece, Spain and Portugal) where there is a strong emphasis within legislation on family obligations to provide care for an elderly or disabled relative. State provision is, therefore, relatively low in such contexts. In contrast to this, Scandinavian countries promote independence of choice with regard to the role of informal carer through the provision of State support services for carers and their families. The authors argue that the role of informal carers is not sufficiently acknowledged nor are carers' needs explicitly addressed in legal and policy developments throughout Europe.

Given the general lack of acknowledgement of the role of informal carers in Europe, it is, therefore, not surprising that European responses to young carers are not easily visible or clearly defined. Aldridge & Becker (2003) describe this absence of response as a 'double jeopardy' because of young carers' status both as children and as carers.

A collaborative study of young carers in Europe (Aldridge *et al.*, 1996) indicated that there was an absence of available research on and attention to the situation of young carers. Brittain (1995) carried out an exploratory study of young carers in France and concluded that French policy makers did not appear to be aware of the problem of young carers and did not consider it to merit further research. The research highlighted divergence of opinion between top level policy makers on the one hand, who feel that young caring is positive in its contribution to character building and, on the other hand, the majority of welfare professionals, who would advocate some form of intervention to protect child carers. Certain changes in French policy directives related to young caring were also outlined in the study. Prior to 1972, a girl's caring duty to her family members was deemed as more important than her educational development. Between 1972 and 1990, a girl's caring duty to her family members was deemed more important than her educational development after age 16. Since 1990, however, girls' and boys' education is considered as more important than a caring duty to family members, but approval is given to situations where boys and girls aged 16 or 17 devote themselves to the care of siblings, at the risk of hindering their educational development.

Gould (1995) carried out an exploratory study of young carers in Sweden. Findings indicated that the general views of policy makers and practitioners were that the welfare system in Sweden was so effective that ease of access to care services meant that there was little possibility of young people finding themselves in a primary caring role. Finally, Dietz & Clasen (1995) carried out an exploratory study of young carers in Germany and found little evidence of acknowledgment of the role of young carers in official documents and research literature. However, they concluded that there may be as many as 72,000 children and young people taking on major responsibilities. Despite the range of professions and organisations contacted, most welfare professionals were unaware of the particular needs of children who care.

Aldridge *et al.* (1993a) point out that 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 without facing the same difficulties as in Britain or in Germany. In cases of mental illness, drug addiction, alcoholism or AIDS, children in all four countries, irrespective of the existing welfare system or family policy objectives and priorities, are generally unable to find the support they need because of the stigma associated with these conditions.

On the whole, in both research and policy for young carers, however, it would appear that the UK is ahead of other countries (Becker *et al.*, 1998). Plans for improving existing support have already been clearly outlined in the National Strategy on Carers UK (H.M. 1999) and some of these recommendations are summarised below.

According to the Strategy, priority will be given to helping local authorities to identify children with additional family burdens and to developing programmes which can ensure that children and young people's education and general development do not suffer. The importance of inter-agency co-operation is also prioritised and the co-ordination of health, education and social services, in particular, is highlighted. The Strategy also emphasises the need for co-operation between adults' and children's services within social service departments, so that, for example, community care assessment of a disabled parent must also pay attention to that disabled person's role as a parent.

The value and importance of raising awareness and providing support through schools is strongly advocated in the Strategy. Plans are outlined to ensure that there is a designated individual in every school who can mediate contact for young carers with social services, health services and young carers' projects. Finally, existing counselling services need to be enhanced in order to promote the independence of young carers. The

difficulties for older teenagers who have been caring for some time to move beyond the family and gain their independence was acknowledged. Under achievement in education and lack of confidence can mean that financial independence is difficult. For this reason, local authorities need to ensure that their counselling and housing services are responsive to the needs of young carers.

This chapter has provided an overview of some primary trends in service and policy development reflected in the literature in the UK and abroad. These developments appear to be more clearly defined and visible in the UK and in Australia when compared with other countries in Europe. Adopting an approach to the issue of young caring needs to encompass a focus on the support needs of the young carers and the differing needs of all family members involved, a focus on the theoretical framework within which we view the needs of the young carer and a focus on the welfare provision within the country in which young caring occurs. In the following chapter we focus on the issue of young caring in Irish society.

In Summary

- Recognition and awareness of the needs of young carers is still to some extent obscured by lack of clarity with regard to definitions and identification of young carers.
- Service and policy development in the area of young carers is more focused and visible in the UK and Australia than, for example, across many countries in Europe.
- Key issues identified in the literature on assessment and services in the UK are identification processes, needs assessment and service approaches.
- The desire for privacy, feelings of stigma and fears about community or professional responses are among the principal barriers to young carers identifying themselves or being identified.
- The needs of young carers are assessed using the *Framework for the assessment of children in need and their families* which provides a focus on the child or young person's developmental needs, the parenting capacity of the disabled or ill cared-for person and family and environmental factors.
- Service approaches have evolved to include a more integrated 'whole family' approach which emphasises the need to provide assistance to all family members and to young carers from ethnic minority groups.
- Similar to service and policy development in the UK, in Australia the focus is on the development of a comprehensive and integrated support system for young carers. Key areas highlighted within this approach are: building community awareness; the education of service providers; the provision of support through schools and third level colleges; developing recreation and youth services focusing on support for young people as they make the transition from adolescence to adulthood.
- Unlike the UK, there was little evidence of awareness and acknowledgement of the problems for young carers in many other countries in Europe. There is greater emphasis on State provision of support to individuals who take on caring roles in Scandinavian countries than, for example, in countries in southern Europe, where there is a strong emphasis on family obligations in legislation.
- A key challenge for future responses, in terms of service and policy development in the area of young carers, involves knowing how to move forward using an approach that is inclusive and encompasses consideration of all family members. Such an approach must incorporate a response to the needs of young carers without pathologising any family member yet without rendering the role of the young carer invisible.

Chapter Five: Young Carers – The Irish Context

A strong tradition of providing care to family members on an informal basis exists in Irish society. Yet, the notion of ‘young carer’ remains, to a great extent, invisible in the research literature in Ireland and in documents outlining policy and service development. This chapter presents a brief overview of existing research on young carers in an Irish context and on studies related to the area of living in families with a disability or illness. Literature on policy and service development for carers is also outlined, especially in the context of disability, in Ireland. Key issues for consideration in a research agenda for young carers are highlighted. Finally, conclusions from the literature review and implications for future research are presented.

A number of features of social and demographic change in Irish society are likely to impact negatively on the existing care support system (Comhairle, 2002). The number of older people (those aged 65 and over) is projected to double between 1996 and 2031 (Central Statistics Office, 1999). In addition to population ageing, an increase in divorce and separation rates may result in additional pressure on public care services as people in these categories may experience greater difficulty in accessing care by a family member (O’Shea, 2000). Women’s participation in the labour force is also increasing rapidly with an increase from just over 30% in 1985 to over 50% in 1999. However, this rate is still lower than in most other EU countries.

Research Context

Pilot study on needs of young carers in Ireland

As previously mentioned, the notion of ‘young carer’ remains hidden in the research literature in an Irish context. However, a pilot study on the needs of young carers in Ireland was undertaken by The Carers Association in 1997. This study was carried out to explore the impact on young people of their roles as carers. The main aims of the study were to obtain an overall picture of contexts in which young people were providing care, including household and demographic characteristics, levels of dependency, caring activities, particular stressors experienced and the level of available support to young carers. In the following sections, a brief overview of the key findings from this pilot study is provided.

The sample included 15 carers (6 male and 9 female), aged between 10 years and 18 years and with an average age of 14 years. Eight of the carers (53%) were caring for their mother, 4 (27%) were caring for their father, 2 children (17%) were caring for a brother and 1 child was caring for a grandmother.

Table 5.1 Relationship of young carer to cared-for person in pilot study on young carers

Cared-for Person	No.	%
Mother	8	53
Father	4	27
Brother	2	13
Grandmother	1	7

Source: Carers Association, (1997)

These young carers were providing care across a range of circumstances including multiple sclerosis, muscular dystrophy, depression and epilepsy. Other reasons cited included “mother’s illness” and a parent’s problem drinking.

Pilot study on young carers in Ireland (The Carers Association, 1997) (n=15)

Average age when participant began caring	→	11 years
Average number of years spent caring	→	3 years and 6 months
Average number of hours per day providing care	→	6 hours per day

The nature of the tasks which these young people had undertaken included preparing meals, doing shopping and taking care of housekeeping. In addition, some young people were providing intimate care, as, for example, dressing, bathing and toileting the cared-for person. Responses to the General Health Questionnaire (GHQ-12) revealed that many of the young carers who participated in the study were in poor general health. Young people stated that they lost sleep as a result of anxiety, experienced constant strain and reported high levels of unhappiness and depression.

Most of the young carers indicated that their school attendance was negatively affected by their care-giving role, with half of the sample missing one day or more from school per week. The worst aspects of caring identified by these young people were:

- Not being able to do what they wanted
- Being denied opportunities to develop a social life
- Being unable to pursue a recreational interest or hobby

Some of the best aspects of providing care included:

- Being able to do something useful and worthwhile
- The knowledge that caring contributed to greater happiness for the cared-for person

Approximately one quarter of the carers rated their relationship with the cared-for person as being 'fair/tolerable' to 'very poor' while the remainder reported that their relationship was 'good' or 'very good'. Many of these young carers indicated that they would like to have a caring role in their future careers as, for example, nursing, working with learning disabilities and childminding.

There was little information on the availability of formal support services accessed by the young carers who participated in the pilot study. The authors point out that this may have been due to the fact that these young carers were not aware of the formal services available or had insufficient knowledge about accessing these services. The level of informal support available to these young carers would also appear to have been quite restricted. The average number of members which young carers identified on their personal network of family and friends was two people.

These findings, although based on a very small sample of young carers, are consistent with many of the findings in the UK and Australia. In particular, restrictions on children and young people's opportunities to develop social networks, the demands on young people's physical and mental well-being and the negative impact on educational and career opportunities are issues which merit further attention and emphasis.

A further study is presently being carried out in University College, Cork to explore the experiences of young carers in the Cork region (Egan, Finnerty & O'Connell, forthcoming). The research is funded by the Combat Poverty Agency under the Third Level Research Scheme and involves sourcing and talking to young people involved in caring responsibilities in a variety of settings. The researchers hope to interview 20 young carers in the course of this research.

Children living with a parent with mental illness

Other related studies carried out in an Irish context, although not directly concerning the issue of children and young people as carers, may help to identify important features in the experiences of children living with a family member with a disability or chronic illness. In 1997, a study was carried out in Trinity College, Dublin to gain insight into the experiences of children living with a parent with schizophrenia in Ireland (Somers, 1997). 37 children between the ages of 8 and 16 years, all of whom had a parent with a confirmed diagnosis of schizophrenia, took part in the study. Among these children, 11 boys and 15 girls had mothers with schizophrenia while 9 boys and 2 girls had a father with schizophrenia. The study adopted a comparative design and included a control group of children with 'well' parents in order to attempt to determine more precisely the effects of living with a parent with schizophrenia.

Key findings

- Children living with a parent with schizophrenia reported fewer family activities than children in the control group
- Children also openly acknowledged the emotional distress, sadness and upset which they had experienced when their parent was ill. One of the most significant findings in the study was the difference between subject children and control children on scores that assessed the children's emotional health and behavioural problems. In all areas, subject children scored higher indicating the presence of more emotional upset and behavioural disturbances
- The stigma associated with mental illness added to the children's upset and fears, and this was particularly associated with the public display of the illness
- The majority of these children (67%) did not speak to anyone outside the family about their parents' illness while the remainder were more likely to talk to their best friend rather than to another adult
- Findings also indicated that children living with a parent with schizophrenia had less contact with extended family members than the control children

Somers (1997) speculates that the negative symptoms of schizophrenia do not facilitate easy communication and interest in maintaining relationships. Stigma and fear may also play a part and families may find it more helpful to cope on their own rather than involving other relatives in the situation.

Consistent with evidence from studies in the UK (Dearden & Becker, 2002; Marsden, 1995) school attendance appeared to be negatively impacted for children living with a parent with schizophrenia. These children of patients attended school less often and it is possible that this absence may have adversely affected their academic performance as the participant children rated themselves as less academically competent than their control counterparts.

On a more positive note, the majority of subject children were no different from the control children in areas of friendships and activities. The study also highlighted the important role played by the 'well' parent in contributing to the well-being of the child. Subject children in the study did not report being burdened by any excess of household tasks. Household tasks did not appear to be taken on as part of a daily routine but rather appeared to be undertaken on an episodic basis, indicating a lack of routine within the daily experiences of these children. Some of the children in the study, particularly female children, wanted more practical help. Somers (1997) argues that home help service, which is not generally available to families with a psychiatrically ill parent (except during hospitalisation) could have a valuable role to play in helping to maintain family routine, in providing a break from household tasks and in having another person available to the children in times of crisis.

Somers (1997) highlights a general lack of service responses to the needs of the children and points out further that adult psychiatric services are designed mainly to meet the needs of the identifiable patient while the family and the children of the patient tend to be excluded from the focus of their support. Lack of knowledge on the part of the children was viewed as contributing to the powerlessness of these children in dealing with their parent's illness and, for some children, inability to help a sick parent because they had no information on how to do so.

Children living with a sibling with acquired brain injury

As part of a more recent study exploring the experiences of children and their families following an acquired brain injury (ABI) (Heary, Hogan & Smyth, 2003), interviews with siblings of children with ABI were carried out to identify how such a life event impacts on children's experiences of family life. A total of 13 siblings were interviewed. For many siblings, the main support need identified was practical help to ease the strain on the family of having to provide high levels of on-going support to the child with ABI, while at the same time coping with the demands of daily family life. Parents were no longer as available to other children due to the necessity of devoting increased time and resources to the child with ABI. Many siblings indicated that they would have liked to receive assistance in the home when their brother or sister was hospitalised. Practical help with cooking meals and carrying out other tasks in the home would have been helpful according to these siblings. Siblings identified their extended families and schools as the principal sources of support for them.

Findings in the study highlighted the fact that many of these children felt empathy with their parents and made every attempt to provide support and help their parents deal with the adversity they were facing. They helped their parents more, for example, with household work, because they felt that this was necessary in the context of the changed demands on the family since the ABI. Most siblings did not actively seek sympathy or understanding from others but appreciated gestures of support which others made in recognition of the strain they were under.

However, it is also worth noting that a key factor which shaped siblings' experiences and responses to living with ABI was the role they perceived themselves to have played, either directly or indirectly, when the trauma or illness occurred. It was evident that siblings wanted to play an active role in helping their injured sibling to recover and that those who felt they had been in a position to take an active role to help their sibling or other family members, appeared to have a more positive view of the outcome of the injury.

Children taking on additional responsibilities in the home

Findings from other studies reinforce the view that playing an active role in helping or caring for family members in times of stress may have a positive impact on children and young people's responses to these critical events. In a study of children's experiences of parental separation in Ireland, involving interviews with 60 children between the ages of 8 and 17 years of age, findings revealed that children willingly undertook additional household tasks following parental separation in order to provide support and assistance to parents bringing up the family alone (Hogan, Halpenny & Greene, 2002). These findings underline the importance of taking into consideration not alone the difficulties for children and young people of providing care to family members, but also the benefits that may accompany the active role which they play.

Consistent with findings from research abroad, particularly in the UK, findings from the studies outlined above reinforce the importance of viewing holistically the issue of young people caring, in terms of adopting a 'whole-family' approach to addressing the needs of young carers and of attempting to identify more clearly aspects of caring which impact positively or negatively on young people's lives.

Policy context

At present, there is no national policy strategy dedicated to young carers in Ireland. However, the present review is informed by a number of national policy initiatives, which are broadly related to the issue of young carers in Irish society. One such initiative is the National Children's Strategy which provides a coherent and inclusive view of childhood and identifies the means through which a range of children's needs may be understood and met (Government of Ireland, 2000). In their pre-budget submission 2004, the Disability Federation of Ireland (DFI) highlights Article 31 of the UN Convention on the Rights of the Child (UN, 1989), which states that the child has the right to rest and to engage in leisure, play and recreational activities and to participate in cultural and artistic activities. However, according to DFI, these rights are being denied to young carers due to the lack of budgets for community-based services such as personal assistants, care attendants and home help (Disability Federation of Ireland, 2003).

In addition, the National Children's Strategy also emphasises that all children should have equal access to educational opportunities. As outlined in previous chapters, taking on the role of carer as a young person can sometimes lead to greater difficulties with regard to school attendance and educational achievement. Reflecting an awareness of these problems, MS Ireland provide specific information for teachers on their website (www.msireland.com) in order to promote awareness of the particular difficulties which may arise for children and young people in a caring role. Among the difficulties outlined are:

- Obstacles to regular and punctual school attendance due to caring tasks within the home and additional tasks such as taking siblings to school
- Negative effects on schoolwork as a result of extra tasks within the home
- Difficulties in concentration due to anxiety about the well-being of a parent

These findings are consistent with findings in the UK (Dearden & Becker, 2002; Marsden, 1995) and indicate that taking on the responsibilities of primary care-giving to a family member may have serious negative implications for children's and young people's educational achievement. The new Education Welfare Board may play a positive role in the provision of advice and assistance to children and young people who take on caring roles with regard to school attendance and academic achievement.

The National Children's Strategy also recognises the empowerment and support of families and communities as the most effective way of supporting children. Consistent with this view, as noted previously in the present review, contemporary perspectives on young carers abroad underline the need to develop policy responses which take into consideration the needs of the whole family, rather than addressing the needs of young carers in isolation.

The Health Strategy, *Quality and Fairness: A Health System for You* (Department of Health and Children, 2001) adopts a definition of health which encompasses a focus on the broader aspects of the quality of life, including the provision of support services to carers within the family. The strategy embraces the notion of holistic health and recognises the wider implications of illness and disability for the family, community and society. The importance of developing services for people with physical and sensory disabilities, which can more effectively meet their needs and the needs of their families, has also been highlighted in *Towards an Independent Future* (Department of Health, 1996) and *A Strategy for Equality* (Commission on the Status of People with Disabilities, 1996) – policy documents promoting equality and more effective service development and provision within the arena of disability.

Disability policy development

In 2002, the National Disability Authority (NDA) commissioned research to investigate the extent and range of service provision, with a view to setting priorities for data strategies, service planning and policies for the equal treatment and inclusion of people with disabilities in Ireland. A series of reports resulted from this process focusing on best practice in the provision of health, educational and transport services for people with disabilities in Ireland. A number of important points highlighted in these reports are worth noting:

- Access to health services for people with disabilities, their families and their carers remains unsatisfactory. Consequences include volunteers, disability organisations and family members/significant others having to fill service gaps
- Services should be provided within a social model of disability which promotes independent living, and should be community-based and provided equitably
- The provision of personal assistance and independent advocacy are considered to be minimal requirements
- People with disabilities have a greater need to access a variety of further education, training and employment services in order to achieve employment in the open labour market

In summary, this approach emphasises much greater attention needs to be given to the social model of disability, independent living and personal assistance in addressing the needs of people with disabilities, their families and their carers. This means addressing disabling barriers that exist, for example, because of a lack of sign language interpretation, appropriate housing or personal assistance.

Minority ethnic people with a disability in Ireland

Barriers to accessing services and to participating in different aspects of society may be particularly difficult to overcome for individuals from ethnic minorities living in Ireland and this, in turn, will have serious implications for children and young people who, consequently, may be obliged to take on the responsibility of caring for family members. A recent exploratory study was carried out by the Equality Authority on minority ethnic people with disabilities, drawing on a review of relevant literature, an examination of national statistical data and one-to-one in-depth interviews with nine participants (Pierce, 2002). Findings from this study indicated that this group is exposed to multiple discriminations based on racism and disability and such discrimination poses very particular challenges to the design and implementation of equality strategies by employers and service providers.

Supporting young carers in an Irish context

In *Strengthening Families for Life*, the Commission on the Family (1998) highlighted the need to acknowledge the extent of unpaid caring work carried out in the home and the community. Families were identified as the main source of care for people with disabilities and the State was considered to have a crucial role to play in planning and resourcing appropriate services to support these individual families. While the presence of any disability in a family causes additional stress and difficulties, it was pointed out that lack of information and specialised services add to the difficulties of a family which has a member with a learning disability.

Endorsing the recommendations of the Commission on the Status of People with Disabilities, the Commission on the Family prioritises efforts to achieve greater equality and possibilities for independent living for people with disabilities. One of the means to achieving this end is the provision of efficient support to those involved in caring responsibilities. One initiative highlighted by the Commission on the Family is the Centre for Independent Living, which, among other programmes, offers training for personal assistants or carers helping people with physical disabilities to live as independent a life as possible.

Priority issues identified in the provision of support to families with a member with a disability include assessment, early intervention, employment, healthcare and geriatric services. A number of gaps in existing service provision to carers have been identified (Comhairle, 2002). Firstly, there is inadequate support for individuals with a disability making the transition from institutional care to informal care in the community. One way in which this gap could be addressed is through the further development of the role of personal assistants within programmes of support (Joint Committee on Family, Community and Social Affairs, 2001). Secondly, communication and co-operation between statutory and voluntary services on the one hand, and between health and housing services on the other, are underdeveloped and remain fragmented. Thirdly, it appears that there is still an element of stigma attached to the use of many support services and this represents a barrier to the uptake of these programmes of support. Fourthly, the public sector's capacity to meet demands for residential care is diminishing. All of these factors converge to create additional demands on the provision of quality care for people with disabilities and suffering from chronic or long-term illness.

Improving support for young carers

Certain key improvements to the carer support system in Ireland which need to be addressed have been identified (Comhairle, 2002). Although no direct reference has been made to the needs of young carers in the context of these improvements, it is clear that many of them would have direct relevance for the well-being of children and young people adopting caring roles in Irish society.

Some of the improvements to be addressed include:

- Greater integration of caring welfare and work opportunities, including greater flexibility for people who wish to undertake caring duties in the home and to alternate between or combine these duties with working outside the home
- Home-based support services
- Greater ease of access to advice and information (Comhairle, 2002)

The caring role may make substantial demands on the mental and physical health and well-being of individuals. As noted in the literature on young carers abroad, one of the difficulties for young people in a caring role is the restriction on opportunities for socialising with peers and engaging in leisure activities. Recommendations outlined in *Supporting Carers* (Comhairle, 2002) include the development of support groups, training programmes and personal development courses for carers. Finally, enhanced ease of access to advice and information for young carers is needed as there is little explicit reference to their particular needs in available documents on caring and disability.

A number of categories of carers with special needs are presented in *Supporting Carers* (Comhairle, 2002). These include elderly carers, carers in rural areas, carers of children with disabilities, carers looking after Alzheimer's and Parkinson's Disease patients, carers of multiple sclerosis patients and carers of people with acquired brain injury. However, notably absent in this list of carers with special needs is the category of carer which involves children or young people, for example under the age of 18.

As outlined in Chapter One of the present review, one of the few explicit references to the problem of young carers in Ireland is contained in *Re-Start the Investment* (Disability Federation of Ireland, 2003). In their pre-budget submission, DFI draw attention to the many differing family situations in which children take on the role of either a full or part-time carer in Irish society. These situations include:

- Single-parent families in which the parent develops a disability
- Children caring for one parent while the other parent is at work
- Children living with a grand-parent
- Children caring for a disabled sibling

Particular emphasis is placed on the demands these caring tasks pose on children and young people. These tasks include:

- Children dispensing medication
- Children coping with parental incontinence
- Children coping with the frustration and depression which can accompany disability
- Children providing care to other siblings and having the responsibility for running the home (DFI, 2003)

According to DFI, children's rights to rest and engage in leisure and recreational activities are seriously undermined by lack of sufficient budgets for community-based services, such as personal assistants, care attendants and home help.

Issues for consideration for a research agenda on young carers in an Irish context

Additional funding for community-based services are required which would help to reduce the need for children and young people to provide care on an everyday basis (DFI, 2003). In light of this, DFI have called for an immediate study on children as carers to ascertain the number of children who are involved as carers in Ireland. Establishing the parameters of young carers in an Irish context and determining the prevalence of young carers in Ireland is but one of the many aspects of the young carers role which needs further exploration. Further research on the nature of the tasks in which young people are involved and the length of time which they experience these responsibilities must be included in a research agenda in this area.

Perhaps more importantly, as highlighted in some of the literature which presents a challenge to research from the young carer's perspective (Newman, 2002; Olsen, 1996), we need to acquire greater insight into the lived experience of young carers on a daily basis and into the meaning and impact of caring roles in their lives. According to these authors, failing to distinguish between the extent to which children are involved in providing care and the perceived impact of this caring role on children's development and well-being, will create confusion when we attempt to distinguish between children in the role of carer and any child living in a family with illness or disability. Understanding the impact of the role of young carer, primarily from the perspective of the young carer themselves, but also from the perspectives of parents and professionals, is essential in order to develop effective policy and programme responses.

One of the key messages which emerges from this review is that comprehensive, 'whole-family' approaches to the development of assessment and services are essential. Approaches which isolate the experiences of either the child as carer or the cared-for person cannot hope to fulfil the needs of those involved in living in families with chronic illness or disability. Similarly, it is necessary to develop appropriate research methods to explore the experiences of young carers and the experiences of their parents and professionals working alongside the family.

Research also needs to be carried out to explore the quality of available support, both formal and informal, to children and young carers living with parental or sibling chronic illness or disability. A number of good practice documents exist to inform and guide further research, in order to tailor precise and effective responses in an Irish context. The potential to develop innovative and attractive interventions to support and sustain young people would be enhanced by such research.

In Summary

- The notion of the young carer is, to a large extent, absent in policy and research literature in an Irish context.
- A pilot study on the needs of young carers in Ireland was undertaken by The Carers Association in 1997. Key findings identified restrictions on children and young people's opportunities to develop social networks, demands on young people's physical and mental well-being and obstacles to educational and career opportunities.
- Other studies carried out in an Irish context, though not directly concerning the issue of children and young people as carers, help to identify important features in young carers' experiences, such as the effects of living with a parent with a mental illness and children living with a sibling with an acquired brain injury.
- Studies have also identified positive effects for young people who undertake caring roles. Such effects are related to playing an active role in contributing to the well-being of a family member with an illness or disability.
- Priority research issues for future exploration in the area of young carers include gaining insight into the lived experience of young carers, into the nature of the caring tasks they undertake and into the meaning and impact of caring roles on their lives.
- At present there is no national policy dedicated to young carers although a number of policy developments related to health, disability, children and their families are relevant to this issue.
- *Supporting Carers* (Comhairle, 2002) emphasises the importance of developing support groups, training programmes and personal development courses for carers. The need to provide a range of home-based support services on an ongoing basis as well as at times of crisis was also highlighted.
- A key message to emerge from a review of the literature on children and young people as carers is that comprehensive, 'whole-family' approaches are needed to address the difficulties experienced by young carers.
- Further research in an Irish context is needed to establish the extent to which young people are engaged in caring, and the impact of this caring on their physical, social, psychological and educational development.
- Research in an Irish context is also needed to explore the quality of available support, both formal and informal, for young people in caring roles. The potential to develop attractive and innovative programmes of support would be facilitated through such research.

Chapter Six: Conclusions and Recommendations

The care and support of family members with high dependency living at home is likely to impose heavy pressure on other family members in the household, and possibly in the extended family. This may prove especially problematic where the dependency extends over a long period of time or is permanent or where there is a severe imbalance between the dependency levels and support needs, on the one hand, and the level of caring capacity available on the other. In some households a number of adults may be able to share the load of physical and emotional labour or they may be able to access help from willing supporters outside the house. On the other hand, given the many variations in family configuration, some households may have few or no other adults able to offer such emotional or physical support. In such instances where there are mainly or only younger household members available to offer support, they may have to play a caring role to a degree that risks impeding their normal opportunities for psychological, social and educational development. Responding to such circumstances requires an effort to re-balance the relationship between demands and capacity to respond. The young carer may certainly need help, but there is also an issue about the family household, as a whole, needing help.

Considerations in reviewing the needs of young carers

A range of theoretical/policy perspectives can be used to appraise the needs of young carers and of the households/families to which they belong. It is suggested that exclusive reliance on one perspective is likely to restrict the range of insights available.

Research suggests that family members access most support, where available, from informal sources (e.g. other family members, friends etc.) rather than from professionals. This has implications for how support programmes should be conceived and delivered.

Support needs and expectations may differ across cultural, economic, social and geographic contexts.

The demands on the young carer may be affected by a range of factors:

- The welfare state climate in a given country
 - Welfare state funding levels
 - Ideology around issues such as family-state relations
 - Relevant traditions
 - Specific factors such as social security and housing support
 - Related factors such as demographics, population density, cultural differentiation, etc.
- The status of the extended family and belief systems around mutual obligations among extended family members in the society
- The level of dependency among people typically needing the support of young carers – this may be related to the quality and availability of treatment and rehabilitation services and environmental or other hazards affecting levels of chronic illness/disability
- Changes in family size, composition and structure
- Gender role expectations
- The level of community integration, cohesion and mutual support at neighbourhood level

- The level of economic and social barriers, opportunity, costs and incentives to those offering informal support to the family or to the young person specifically
- The young person's own beliefs, perceptions and capacity and the level of informal and formal support accessible to them
- The degree of sensitivity in various service systems in relation to the needs of young carers, e.g.
 - Education providers
 - Mental health professionals
 - Disability services

Given the complex range and interaction of factors bearing on the experiences of young carers, it is clear that research is important in developing understanding and responses in relation to the needs of the young carer.

Research agenda

The following are a series of research questions that seem relevant to deepening our understanding of the support needs, issues and contexts relevant to young carers in the home:

- How many young people find themselves playing a role as main (or very significant) carer in their home?
- What are the characteristics of these young people and the contexts in which their caring roles arise?
- What are the developmental implications for the young people involved of their role as carer over time and what factors mediate these impacts?
- What are the effects of caring on young people's educational achievement?
- What are the support needs of the family system and of the young carer specifically day-to-day and what models of response to these day-to-day (or longer term) needs seem helpful based on evidence from relevant case studies and from international evidence?
- In what ways may families whose circumstances oblige a young carer to play a key role have different support/intervention needs compared to other families in the community?
- What neighbourhood, cultural or other factors may mediate support needs and responses?
- What are relevant demographic trends that may affect the expectations made of young carers and their experiences (e.g. family size, separation and divorce, lone parent headed households, parental participation in the labour force)?
- What are key perceptions and attitudes among relevant professionals towards the young carer?
- What types of support efforts have what effects in what circumstances, and what factors seem to affect the emergence and development of such programmes, and the take-up and impact of such programmes?

Answering these questions would require a variety of approaches involving, among other things various combinations of the following:

- Secondary analysis of available statistical and administrative data
- Policy analysis
- Cross sectional studies (at a point in time)
- Longitudinal research (tracking developments in relevant cases over time)
- Research based on interviews, observation, case studies, etc.
- Action research

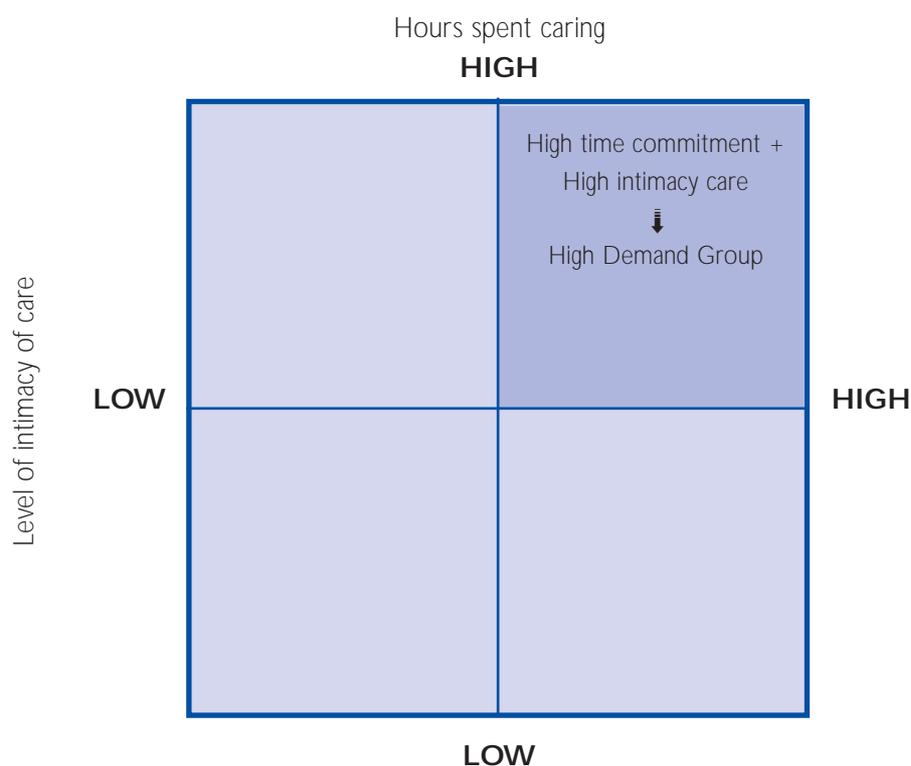
Research findings are likely to be more robust where they are based on multiple methods and where relevant they track developments over time.

Next steps

On the basis of the evidence reviewed in this report (and the comments of the study's advisory group which are gratefully acknowledged), the authors would propose the following as next steps in formulating and pursuing a policy agenda in relation to this issue:

- It is recommended that the Department of Health and Children should specifically accept responsibility for policy in relation to young carers, and that delivering appropriate supports on the ground be an explicit function of the Health Service. It is also suggested that other relevant key policy players, e.g. the National Children's Office, the Mental Health Commission, local directors of mental health services, regional directors of disability services should also play a key role in identifying and formulating responses to need at a system and case level.
- It is recommended that situations where a significant care responsibility is being undertaken by someone under 21 be flagged on the Physical and Sensory Database.
- It is recommended that assessments of need for personal assistance which flow from the work of the Personal Assistance Working Group should assign a weight to situations where significant care responsibilities fall on children and young people.
- Policy priorities should include: provision of additional care supports where families rely currently on young carers; providing substitute care to enable young carers participate fully in their studies, and allow for reasonable social life and social contacts with their peers; and support with the emotional and psychological issues around their care role and the illness of the parent/cared for person.
- To explore how best supports for young carer might be put in place, it is proposed that a set of pilot schemes should be developed with the support of the Health Service Executive. These pilot schemes should be operated on action-research principles and evaluated to help evolve responses to need, based on Irish conditions. It is suggested that the pilot schemes should prioritise the needs of single-handed young carers and those who carry a heavy degree of intimate personal care (see Figure 1.9), that is those who have to give more than 15 hours per week to caring duties and whose duties also involve a substantial degree of intimate care.

Figure 1.9 Levels of time commitment and intimacy of care for young carers



These schemes should cover what are probably the typical sets of circumstances in which the young carer role may emerge: where an unsupported parent/young person's former primary carer has serious mental health problems, or progressively debilitating illness, or chronic illness/dependency, or increasing dependency in old age. It is recommended that there should be four such pilot schemes, one linked to a community mental health service, one linked to an area public health nursing team and two linked to NGO providers in the disability field, e.g. MS Society. It is considered that this spread will help to capture the diversity of needs, conditions and responses that will have to be accommodated when more comprehensive national provision is being rolled out. The aim of the pilot schemes will be to develop realistic, grounded, culturally appropriate models of intervention and support that will respond effectively to actual sets of circumstances. Particular attention will be paid to developing educational and peer support to help counteract risks of educational delay or social isolation that may otherwise accrue to a young carer.

- A programme to raise public awareness in the media and other relevant contexts.
- An information campaign targeting families with young carers.
- Educational inputs at pre-service and in-service level for all health, educational and social service professionals to sensitise them to the needs of young carers and their families.

Further research

- A research programme aimed at exploring the questions posed above in the research agenda section is recommended. Such a research programme could involve a preliminary survey-type study to identify:
 - Extent to which young people provide primary care in the family (and the degree of intimacy, exclusive responsibility and stress involved)
 - Contexts in which caring arises
 - Differing characteristics of young carers

Follow-up studies within such a programme could adopt a qualitative design to explore children's, young people's and other family members' perspectives on caring for a family member with a chronic illness or disability.

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