

**Hidden Voices:
an exploratory study of young carers in Cork**

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Abstract

Informal provision of care by family members is one of the foundations of care provision in Ireland. The unstated assumption amongst policy makers and service providers is that this care is provided by adults. This however overlooks hidden young carers - young people under the age of eighteen years who carry out extensive, ongoing and often onerous caring responsibilities for family members. These hidden young carers and their experiences during and after caring are the focus of this research. Using a small sample of current and former young carers from Cork city and county, the study identifies the nature of the caring responsibilities they have undertaken and the significant and often adverse impact this has on various aspects of their lives. Service providers consulted in the second phase of the research reported a low level of knowledge or understanding of hidden young carers. This highlights the importance of greater recognition at the level of policy formulation, and appropriately structured responses to their needs at the level of service provision.

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1 Introduction

Informal provision of care by family members of elderly, ill and disabled persons is one of the foundations of care provision in Ireland. It is ingrained in the fabric of Irish society that caring for those who require it is a duty and an obligation and this is undertaken in a largely unquestioned and frequently unnoticed manner. Despite the development of welfare and social policies in Ireland in recent decades the tradition of reliance on informal care remains strong and in many respects official policies on the personal social services are predicated in this continuing. Informal care is a valuable social policy resource which is increasingly acknowledged at official level as a central plank of welfare provision through, for instance, an increased range of supports and funding for carers and support for organisations whose brief is to promote awareness of and lobby on behalf of carers.

The primary assumption underpinning much of this informal care is that it is provided by adult carers, and this undoubtedly is the case for the vast majority of care provided. It is a testament to the strong bonds of loyalty and obligation between and within households and across the generations. There are, however, other actors who provide informal care who are rarely mentioned in discussions on informal care and are scarcely acknowledged as existing. These are 'hidden young carers', in other words young people under the age of eighteen years who carry out extensive, ongoing and often onerous caring responsibilities for family members who have no one else to look after them.

These hidden young carers and their experiences during and after caring are the focus of this research. Using a small sample of current and former young carers from Cork city and county, the study attempts to identify the nature of the caring responsibilities they have undertaken and the impact this has on various aspects of their lives, both in the short term and in the longer term throughout their later (adult) lives.

In essence the research seeks to give a voice to young carers who are rarely heard and largely hidden, in terms of recognition of the caring roles they fulfil, in terms of the impact on their lives, and in terms of policies for carers more generally.

The research effectively follows up on a recommendation arising from the most comprehensive review of policy and perspectives on young carers in Ireland undertaken by Halpenny and Gilligan in 2004. This stated that:

priority research issues for further exploration in the area of young carers include gaining insight to 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 (Halpenny and Gilligan, 2004:47).

1.1 Research Officer, Research Advisory Group and Dissemination of Interview Findings

A research officer, Ms Orla Egan, was employed to undertake the interviews with young carers.

The research process was guided by an advisory group comprised of representatives of the Carers Association, the Department of Social and Family Affairs, Cork City Partnership, Cork Rapid Programme, and the Office for Social Inclusion of Cork City Council. Following on from the interviews with current and former young carers, two additional elements were included in the research process.

Firstly, an audit of organisations and service providers involved in providing services and supports to carers in the Cork area was undertaken. Among the aims was to assess the extent of recognition of the roles fulfilled by young carers, the impacts on their lives, and the needs that caring responsibilities generated for them. These organisations were also

circulated with the findings of the interviews for consideration in the context of their own remit and service provision.

Secondly, a day-long seminar was held to disseminate and discuss the findings of the research. This seminar provided a valuable forum to heighten awareness with voluntary and statutory bodies and to promote thinking about joined-up strategies through which the needs of young carers could be responded to in practical terms.

1.2 Report Outline

Chapter two provides an overview of research and policy in relation to young carers in Ireland. Chapter three presents the methods and findings of the primary research into the experiences and attitudes of current and former young carers in Cork city and county. Fieldwork was conducted by Ms Orla Egan. Chapter four presents the research conclusions and recommendations. Summary accounts of the audit of services and the seminar of service providers are provided in Appendices 1 and 2 respectively.

2 Research and Policy on Young Carers in Ireland

2.1 Existing Research on Young Carers in Ireland

There is little by way of a young carer research literature in Ireland. The existing research overwhelmingly focuses on adult caregivers (see e.g. O'Donovan et al., 1997; Garavan et al., 2001). As mentioned above, Halpenny and Gilligan (2004) have undertaken a wide-ranging literature review on young carers which surveyed the international literature and policy context. However, their report did not undertake any primary research with hidden young carers.

In Ireland two short studies related to young carers were carried out in the mid-1990s. The first was by Multiple Sclerosis Ireland (1996) on MS sufferers and the second was a pilot study by Carers Association (Ireland) (1997) which aimed to obtain an overall picture of the contexts within which young people were providing care including levels of dependency, caring activities and levels of support available to young carers. However, the focus of these studies differed from the current one. The MS Ireland study was focused on care needs of MS sufferers and the source of the care they received while the Carers Association research focused on the nature of the tasks and extent of caring undertaken by young people rather than exploring the impacts on young carers and their attitudes and feelings in relation to their caring responsibilities.

As a result this current research represents the first in-depth qualitative study which specifically gives a voice to hidden young carers in Ireland. Furthermore, in an effort to assess the long-term effect of caring on later life, the responses of a number of former young carers who are now adults have been included. Such voices give a valuable additional insight into the often life-long effects that disproportionate caring as a young person can lead to.

2.2 Prevalence of Young Carers in Ireland

This study is of a qualitative nature and does not purport to undertake an empirical assessment of the number of young carers in Ireland. However,

rough estimates can be made to gauge the extent of caring by young people in Ireland from the data provided by the Census. The Census of Ireland (Volume 10 Carers and Disability) 2002 and 2006 provides data on caring activities within the population as a whole. However, this includes only persons from the age of 15 years upwards and therefore the caring contributions of young people under the age of 15 are not enumerated.

In an analysis of the Census 2002 returns on caring, Halpenny and Gilligan reported that a total of 148,754 people in Ireland provided regular, unpaid, personal help to a family member or friend with a long-term illness, problem or disability; 57,480 of these were males and 91,274 were females and represented 3.8 per cent and 5.8 per cent of all males and females nationally and 4.8 per cent of the total population aged over 15 years. In the period between the Census of 2002 and that of 2006 the proportion of the population aged 15 years and over providing care grew marginally to 160,917, though in proportional terms it remained static at 4.8 per cent of the population as a whole.

With respect to persons in younger age groups who provide care, Census 2002 data are only available for persons from the age of 15 years upwards. A total of 2,996 persons aged between 15 and 17 years were recorded as providing unpaid personal care. Of these 819 were aged 15 years, 103 were aged 16 and 1,140 were aged 17, which in total accounted for 2 per cent of the total caring population. It is not possible to make comparisons between 2002 and 2006 as the latter census did not publish figures for persons in younger age groups who provide care.

2.3 Defining Young Carers

Halpenny and Gilligan (2004) have asserted that, due to the complexity and diversity surrounding the role of young carers, a satisfactory definition has proved difficult. However, a range of factors can be cited which set young carers apart from both adult carers and other young children within families who do not take on a caring role. According to Halpenny and Gilligan, young carers are usually under the age of 18 and are 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 (Halpenny and Gilligan, 2004:13).

A range of additional criteria are also relevant to the definition of young carers such as the amount of caring and whether caring is primary or secondary. Furthermore, Halpenny and Gilligan, citing Banks et al. (2002), note that the question of whether or not young people include themselves as carers is important in any definition.

Several definitions of young carers can be identified within the literature on social work and from caring organisations. 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 (cited in Halpenny and Gilligan, 2004:14).

The Carers Association in the UK has proposed a definition of young carers as being persons who are 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).

An alternative definition has been proposed by Thomas et al. (2003) which they assert is more inclusive than standard definitions of young carers as it reflects an acknowledgement of the needs of the young carers themselves and distinguishes these from the needs of family members who are ill or disabled. Accordingly, Thomas et al. identify the young carer as:

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 (Thomas et al., cited in Halpenny and Gilligan, 2004:14).

This definition would appear to be a more comprehensive and inclusive one insofar as it is founded on a recognition that the caring responsibilities carried out by young people create particular needs which must be responded to. In the context of the research presented in this report it would seem to be the most suitable definition.

2.3.1 Identifying Young Carers

Difficulties in identifying and researching young carers arises partly out of the highly private nature of the role and the fear of both the young carer and the adult they are caring for that either will be taken away from the family setting. This is a particular issue when it comes to recognising young carers. There is fear on the part of the adult that the young carer will be taken away (Multiple Sclerosis Ireland, 2003; House of Commons Select Committee on Children, Schools and Families, 2008). In addition, there is fear on the part of the young carer that the relative he/she cares 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 him/her (Gould, 1995; Watson, 1999, cited in Halpenny and Gilligan, 2004:13).

A further issue in relation to service provision is that many professionals such as teachers who deal directly with children, or those such as GPs and mental health professionals who deal directly with those being cared for, may not be sufficiently aware, informed or resourced in addressing the young carers issue (Gillam et al., 2003; Barnardo's, 2006; House of Commons Select Committee on Children, Schools and Families, 2008).

2.4 Young Carers: Theoretical Approaches

According to Becker et al. (1998), there are a number of key theoretical paradigms which inform perspectives on young carers. These paradigms have evolved over time, and according to Halpenny and Gilligan, 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 (Halpenny and Gilligan, 2004:14).

Becker et al. (1998), outline these key perspectives.

- Firstly, there is the medical model, which originated in the early 1950s and is primarily concerned with the impact of ill-health and disability on families, including children.
- Secondly, there is the young carers perspective, which 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.
- Thirdly, there is the social model of disability, which 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.

- Fourthly, there is the family perspective, which is still evolving and becoming more clearly defined in service and policy responses to young carers. Becker et al. suggest that 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 (Becker et al., 1998).

2.5 An Overview of Different Perspectives

2.5.1 The Medical Model

In the course of their discussion Becker et al. (1998) point out that the medical literature recognises the care given by children as secondary to the illness or disability itself, resulting in particular emphasis being placed on the patient and only secondary attention being given to the impact on remaining family members. Their survey of the medically-informed literature on young carers revealed that the focus was on child maladjustment, behavioural problems and genetic and psychological risk factors, while according to Olgas, work relating to 'specific sensory disabilities such as hearing and visual impairment tended to focus on issues of communication and learning acquisition in children' (Olgas, 1975 cited in Halpenny and Gilligan, 2004).

Becker et al. have also identified within the medical literature the effects of changing role patterns in families where a member has a specific disability or chronic illness. In such circumstances children's roles are modified when they take on additional caring responsibilities in the home. Other potential effects of children assuming caring roles are related to educational achievement and transition to adulthood. Arnoud (1959) has suggested that caring can lead to 'over-compliance' and loss of emotional spontaneity in children. However, US research into former young carers found no evidence of long-term mental health or emotional problems in this group (Kachorek and Shifren, 2003, cited in Social Care Institute for Excellence, 2005).

However, the potentially positive effects which can arise from care-giving have also been noted. Sturges (1978) commented that in the short term care-giving and providing assistance may have positive effects in that it can provide security for the child and enable the child to feel that he/she is actively involved in contributing to positive outcomes for the cared-for person (cited in Halpenny and Gilligan, 2004). Similarly, the work of Power (1977) is noted as suggesting the positive effects of caring in the context of parental illness where caring could be viewed as a source of hope in contributing to the improvement of the parent's functioning, though this was tempered by the concern that long-term positive effects can be outweighed by the resultant obstacles to social interaction which accompany such a role.

Halpenny and Gilligan (2004) contend that maintaining a broad focus on perspectives regarding young carers is an important issue arising from the early medically-informed studies of young carers. They note the emphasis of Becker et al. in relation to the moderating effects of social factors on the experiences and opportunities for children living with parental illness and disability. They further note that the concern of much of the more recent work following the medically-influenced literature is marked by an emphasis on 'support that is family-centred and reinforces arguments put forward in some of the core recent work on young carers' (Halpenny and Gilligan, 2004:15).

2.5.2 The Young Carers Perspective

The young carers perspective, pioneered by the Young Carers Research Group at Loughborough University since the early 1990s, asserts that the extent and nature of children's caring roles is inextricably linked to the underlying reasons for them assuming such roles in the first place.

According to Halpenny and Gilligan, 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. Why children become carers is the outcome of a complex set of factors related to the illness or disability of the parent, the structure of the family, gender issues, and the extent and nature of external supports.

Wider social policy measures also play a role as Aldridge and Becker (1997:4) have noted: '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, organisation and practice' (cited in Halpenny and Giligan, 2004).

2.5.3 The Social Model of Disability

This model views disability as an outcome of social structures and processes, and limitations and obstacles to opportunities and life chances are viewed as arising out of such social processes (Oliver, 1996; Oliver and Barnes, 1998; Marks, 2001). On this basis an individual impairment is interpreted in terms of the social and environmental factors that create the barriers to participation in society by persons with a disability. In essence the problem lies with the social barriers that prevent participation rather than being inherent to the individual or the individual's condition. The social model contrasts with the medical or individualised model which equates the person's impairment with his/her disability and fails to contextualise it in the broader social context.

The social model of disability has important and critical implications for understanding the role of young carers. 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. Halpenny and Gilligan (2004) note that 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 and Morris, 1995; Parker and Olsen, 1995; Newman, 2002). 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, i.e. young people would be freed from the burden of care.

2.5.4 The Family Perspective

The family perspective on young carers highlights a shift in emphasis from viewing them in isolation towards a consideration of the caring and support needs of the family as a whole. This arises from a recognition that illness or disability can alter the organisation of the basic care-giving system within families (Altschuler, 1997, cited in Halpenny and Gilligan, 2004). Potentially contradictory systems of care-giving can exist side by side within the family because:

... 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, cited in Halpenny and Gilligan, 2004:17).

The family perspective would appear to offer a valuable framework for how the needs of young carers and their families can be responded to in terms of policy and services. The emphasis of the whole-family approach shifts the focus of strategy for young carers from protection to prevention and from young carers and those they are caring for as separate individuals towards the needs and rights of the family as a whole.

2.5.5 Alternative Views on Young Carers

A number of challenges have been proposed to the research on young carers. These can be summarised as follows: the exclusive focus on negative outcomes for children who take on caring roles; the absence of

recognition of the resilience of children and young people in caring roles and the potential for positive outcomes to emerge from their experiences; the effective exclusion of a focus on the ill or disabled individual; and the lack of robust data exemplifying the impact of caring on children and young people. (See Cass 2008 for a discussion of these issues in an Australian setting.) Further criticisms relate to the absence of differentiation between the contexts of caring and their consequences.

Halpenny and Gilligan note that challenges to the research on young carers 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. These challenges, along with the evolving research from the perspectives referred to above, offer important guidance for evaluating and interpreting the caring roles fulfilled by young carers. The diversity of perspectives highlights the need for broadly based and responsive frameworks to ensure that research on young carers most effectively captures the lived experiences of young carers and those they care for, highlights the impact of caring responsibilities on their quality of life and life chances, and raises awareness of the deficits that need to be addressed at the level of policy and provision.

2.6 Policy and Provision in Ireland

In the Irish context, recognition and responses to the existence and needs of young carers could be best described as uneven. For example, no reference to young carers is made in the major policy document relating to children in Ireland – the National Children’s Strategy 2000–2010. This is a serious gap in official recognition and awareness of a highly vulnerable segment of the child population. Many other policy and research reports in relation to children in Ireland also omit any reference to the existence and contribution of young carers. Specifically, the issue of young carers is not mentioned in the Office for Social Inclusion (2007) publication *A Social Portrait of Children in Ireland*. Additionally, no national policy strategy exists with an explicit focus on young carers. Traditionally it has been the needs of adult carers

that have been the focus of lobbying, research, policy statements and service provision in this area. For example, there is a noteworthy absence of mention of the 'young carer' issue in the Comhairle document *Supporting Carers* (2002) or in The Joint Oireachtas *Report on the Position of Full-Time Carers* (2003b).

It is certainly the case that the issue of informal care has enjoyed greater political and policy attention in recent years. The Carers Association was one of the voluntary groups involved in negotiating the national partnership agreement. The agreement, *Towards 2016, the National Action Plan on Social Inclusion* and the *Programme for Government*, contain several references to carers; with a focus on income supports for adult carers, and an emerging emphasis on training and consultation (see also Browne, 2005 for a discussion of the evolution of income supports for adult family carers).

However, it is evident that such documents understand the role of carer to be performed by adults. For example, in those documents adopting the current life-cycle approach to the welfare state (NESC, 2005), issues relating to carers are outlined in the section on 'people of working age' rather than also in the section on 'children'.

Recent reports on caring by Cullen et al. (2004) and by Browne (2005) similarly make little or no mention of young carers. There is, however, a passing acknowledgement in the recently published carers consultation report (Carer's Association of Ireland, Carer Alliance Ireland and Caring for Carers Ireland, 2008:28) that '... carers comprise a very heterogeneous group Caring is carried out by all age groups throughout the life cycle, including children.'

Evidence is now emerging of a growing awareness of the roles played by young carers and the subsequent needs of these young people. Recent policy documents arising from the social partnership process overtly acknowledge the existence of young carers as a specific cohort within the caring population overall, especially where they may be undertaking

'inappropriate care roles'. Arising from the participation of the Carers Association in the negotiation of the current national partnership agreement, *Towards 2016*, there is a commitment to undertake research on 'the extent, degree and impact' of caring on the lives of the children concerned. It goes on to commit to the development of supports to 'alleviate specific problem areas identified for children', based on the findings of the research (Government of Ireland, 2006: 46).

Some recognition of young carers is also evident in terms of the development and implementation of equality policies. In a report entitled *Implementing Equality for Carers*, the Equality Authority (2005) highlights concerns in respect of the rights of children who find themselves taking on excessive or inappropriate caring responsibilities. The Equality Authority noted that the extent and nature of the responsibilities carried by young carers is largely unknown and that 'it is highly undesirable for young people to have such a heavy burden of caring responsibilities'.

In terms of protecting the rights of such children, the Equality Authority asserts that 'the state has a clear responsibility to provide a full range of services for young carers'. These services must begin by identifying the young carers and follow on by the provision of practical supports such as counselling, respite, access to education, social inclusion and meeting personal development needs (Equality Authority, 2005). To progress the rights agenda of young carers the Authority recommended that their needs be addressed as a matter of urgency by such agencies as the Health Service Executive and Department of Education and Science.

The UN Convention on the Rights of the Child provides a test of how well Irish policy and provision performs in respect of the recognition and needs of young carers. When measured against a number of the articles contained in the Convention, significant deficits are revealed. For instance, it is arguable that the current poor levels of acknowledgement and appropriate responses for young carers in Ireland means that the state does not adhere to the overarching principles of Article 4 which asserts that 'States Parties shall

undertake all appropriate legislative, administrative and other measures for the implementation of the rights recognised in the present Convention' (UN 1989 Article 4: 44.25). Similarly, the absence of support services for young carers to enjoy their rights to rest, leisure, recreation, appropriate to their age is in contravention of Article 31. Undertaking excessive caring responsibilities without appropriate supports can also be interpreted as running counter to the right to education (Article 28) in relation to children being in a position to access and attend school.

The sporadic nature of policy recognition in Ireland is also characteristic of many other countries, with the UK and Australia being notable exceptions.. In the UK, for example, social services departments can assess young carers under Section 17 of the Children Act (1989) as children in need, or as carers – at any age – under the 1995 Carers (Recognition and Services) Act. The Carers and Disabled Children Act (2000) offers an opportunity for carers over the age of 16 to receive an assessment and services, including direct payments, in their own right (Dearden and Becker, 2004). The Every Child Matters policy initiative supplies detailed guidelines for relevant service providers in identifying and assessing young carers (Princess Royal Trust, 2005). The recently launched (UK) national carers' strategy (H.M. Government, 2008) also includes a section on young carers, mainly in the area of education and awareness-raising among service providers.

In Australia, the improved visibility of young carers emerged from the advocacy work of NGOs in the area, leading to a number of research studies in the last 10 years (Cass, 2007). In particular, the Commonwealth Department of Family and Community Services funded the Carers Association to undertake national research on young carers. Most interventions targeted at young carers specifically are channeled through voluntary organisations such as regional carers associations, comprising young carers websites, information, support groups and respite (see e.g. Carers Association, 2008). However, by contrast with the UK, there is no legal entitlement to assessment and services in Australia.

This review has examined the literature relating to the definition of young carers, the various theoretical perspectives by which to analyse and interpret their roles, their relationships with those they care for, and highlighted aspects of the policy responses nationally and international. The review of theoretical perspectives offers a range of conceptual approaches to interpreting, understanding and responding to the young carers phenomenon. It has shown how recent thinking on young carers has become more broadly based in comparison to earlier ideas with a shift evident from a concentration on the impacts on children who are contending with situations of ongoing illness or disability to exploring the wider contexts within which they exist such as low income, poverty and socio-economic marginalization, and social networks. The coping capacity of children who care is highlighted by other strands of the literature – partly in response to a view that there may be positive outcomes for young carers arising from their responsibilities in terms of stronger relationships with those they care for, resilience, coping capacity and acquisition of vocational skills. The policy review noted the sporadic and uneven attention paid to young carers in the Irish context, which contrasts with the international experience. The policy gaps and subsequent deficits in services and supports for young carers in Ireland pose major challenges to policy makers and statutory services in ensuring that the basic rights of such young people are respected and vindicated.

3 Interviews with Hidden Young Carers in Cork

3.1 Research Design and Methodology

In attempting to identify potential participants, contact was made with a wide range of organisations and individuals who work with families and young people in the wider Cork area and who could be in a position to identify and introduce young carers. Contact was made by phone and/or by letter.

Those contacted in relation to the research included:

- Youth organisations
- Educational establishments
- School completion programmes
- Community development programmes
- Family centres
- RAPID co-ordinators
- Sporting clubs
- Carers' organisations
- Disability groups.

A number of network meetings were also attended to publicise the research and to ask for assistance in identifying potential participants. This included the Knocknaheeny Network and a platform meeting of the Disability Federation of Ireland, Cork and Kerry Branch.

Extensive efforts were made through the resources of the advisory group and the HSE South to publicise the research, particularly amongst Public Health Nurses who are in direct contact with the families of people who are ill or disabled.

Unfortunately, however, most of those contacted failed to identify any young carers. This does not imply that young carers do not exist, but rather reflects

the invisibility of young carers and the hidden nature of the issues being researched, as discussed in Chapter one. Many of those contacted were unaware that young people undertake significant caring responsibilities. Others were aware of a number of young carers, but were reluctant to put the researcher in contact with them for fear of exacerbating already difficult situations.

The research was conducted primarily through qualitative, semi-structured interviews with young carers and former young carers. The interviews were carried out by an experienced social researcher, Ms Orla Egan who was highly cognisant both in arranging and conducting the interviews of the sensitive nature of the material involved. Interviews were undertaken at locations chosen by the interviewees – where they felt comfortable - such as youth centres, cafés etc. The interviews ranged in duration from fifty minutes to two hours and the questions were posed in an informal manner cognisant of the age of interviewees. (see Appendix 3)

The young carers and former young carers who participated in this research were identified through the following channels:

- Youthreach Knocknaheeny
- Youthreach Bandon
- Carer's Support Group, Cork
- Multiple Sclerosis Society, Cork

Personal contact: These were persons who took up the invitation, as posted on noticeboards and email lists of the organisations listed above, to contact the researchers directly.

3.2 Participant Profile

Ten interviews overall were carried out as part of this research from 2004 onwards. This included nine interviews with young carers – comprising five young carers and four former young carers. Two of the young carers are siblings. One person who is being cared for by a young carer was also interviewed.

The low number of interviews reflects the difficulties encountered in locating and contacting young carers (as outlined above). However, it is clear that the interviews carried out have highlighted the major issues of concern to young carers and demonstrate the diverse impacts of caring on young people's lives.

3.2.1 Age and Gender

The interview sample reflects a range of age groups, with an even balance of male and female participants (Table 3.1). While no young carers under twelve years of age were interviewed, a number of the participants had been caring from as young as four or five years of age.

AGE	FEMALE	MALE	TOTAL
12 – 13	1	1	2
14 – 15	0	2	2
16 – 17	0	0	0
18 – 19	1	0	1
20s	0	1	1
30s	1	0	1
40s	1	0	1
50s	1	0	1
TOTAL	5	4	9

Table 3.1: Interview participants by age and gender

3.2.2 Geographical Distribution

The young carers and former young carers interviewed came from various parts of Cork city and county (Table 3.2).

AREA	NUMBER
Ballyphehane	2
Bandon	1
Blarney	1
Douglas	2

Gurranabraher	2
Togher	1

Table 3.2: Geographical distribution of participants

3.2.3 Person Cared for and Reason for Caring

Eight of the nine young carers and former young carers interviewed were caring for their mother. The ninth interviewee took over caring for a younger sister when her mother suffered a nervous breakdown.

Four of the young carers and former young carers were caring for more than one person. In three of these cases, the carer also took responsibility for the care of a younger sibling, as their mother was unable to do so. The fourth carer was responsible for caring for three people: her mother, aunt and grandfather.

The young carers and former young carers were taking care of relatives with a mixture of physical disability and mental health problems. Seven of the relatives being cared for had some form of physical disability. Four suffered from mental health problems. Three needed care because of their age (younger siblings).

Person Cared For	Reason Care Needed
Mother	Mother had stroke causing mobility difficulties and partial paralysis.
Sister	Sister has Down's Syndrome. Mother had nervous breakdown and was unable to care for her daughter.
Mother Aunt Grandfather	Mother had mental illness. Aunt had Schizophrenia. Grandfather was elderly (90s).
Mother	Mother has Multiple Sclerosis.
Sister/ Mother	Mother has Manic Depression – unable to care for youngest daughter.

Mother	Mother has Multiple Sclerosis.
Mother	Mother has Multiple Sclerosis.
Mother and Brother	Mother physically disabled. Father alcoholic. Caring for younger brother.
Mother and Brother	Mother had Recurrent Depressive Disorder. Caring for younger brother.

Table 3.3: Person cared for and reason for care

3.2.4 Length of Time Caring

Four of the young carers and former young carers interviewed began caring when they were less than six years of age. A total of five young carers and former young carers began caring under the age of ten. Four young carers and former young carers began caring in their teenage years.

Of the current young carers, three began caring under the age of six, while the remaining two began caring at eleven or twelve years of age. Thus all of the current young carers began caring at age twelve or younger. All the young carers and former young carers interviewed had been caring for a long period of time, from a minimum of around four years up to over forty years of caring.

All the young carers and former young carers interviewed were – or had been – caring on a daily basis, although there was variation in the nature and intensity of the caring.

Current Age	Age Began Caring	No. Years Caring	Frequency of Care
12	5	7	Daily
13	6	7	Daily
14	4	10	Daily
15	~ 11	~ 4	Daily
18	12	6	Daily
25	18	7	Daily
35	15 (until 20)	5	Daily

44	9	33	Daily
50	Toddler	~ 45	Daily

Table 3.4: Age beginning caring/ duration and frequency of caring

3.2.5 Family Circumstances

Four of the young carers and former young carers lived in households where the parents had separated and the father was absent. Three of these lived with siblings and their mother.

The father was present in the home of five of the young carers and former young carers interviewed. However, in four of these cases the father was out at work, leaving the primary caring responsibilities to the young carer. In the other case, the father had given up work to assume prime caring of the mother, thus relieving somewhat the caring responsibilities of the young carer.

3.3 Nature and Extent of Caring Responsibilities

The nature and extent of caring responsibilities varied among the young carers and former young carers interviewed.

One former young carer was caring for three people – her mother, aunt and grandfather – from when she was a toddler. Her mother and aunt both suffered from mental illness, while the grandfather was elderly and physically ill. She cared for all of them daily and was also often up at night with them. Her father was present but was working, so she had primary responsibility for caring for them. A younger brother was also present but he was not expected to do the caring work. The caring involved personal care (dressing, emptying commodes, etc.), housework and cooking as well as the need to constantly watch her aunt who was inclined to wander the roads, and her mother who was paranoid and would keep hiding things in the house.

Another former young carer took care of her sister, who has Down's syndrome, from when she was nine years old and her sister was a baby. Her mother suffered a nervous breakdown and was unable to care for her. Her father was working, an older sister had left the country and her brothers played no role in caring. Her father died when she was sixteen, leaving her as primary carer. Caring responsibilities included personal care, cooking, shopping and housework. She also took care of her mother who was self-neglecting. At a later stage she arranged and monitored education and rehabilitative care for her sister.

Two young carers who are siblings provide a great deal of physical and personal care in addition to assisting with housework and cooking. This includes helping their mother in and out of bed, in and out of the car, on to and off the toilet and assisting with dressing. The daughter, on occasion, has had to assist in changing her mother's catheter.

Another young carer takes care of her younger sister (six years old) and used to also care for a younger brother. This involved all the tasks associated with caring for a young child as well as trying to make sure her brother went to school. She also has to watch her mother, who is manic depressive, and ensure that she has not fallen asleep smoking or left all the doors unlocked.

One young carer described his caring responsibilities as: 'I just give an old hand like.' This entailed daily assistance with housework, shopping and getting his mother's medication. A key element was regular checking on his mother (every few hours) to see if she was okay or if she needed anything and staying with her if she was unwell.

3.4 Feelings about Caring Responsibilities

Interview participants expressed a range of emotions in relation to their caring role: acceptance, resentment, anger, annoyance, stress, trauma and upset.

Some felt that caring for their relative, while difficult, was just something you do because of family bonds.

'It's not all that bad like. The odd time there you'd get fed up of it like. But what can I do, it's my mam. You have to look after her. She does the same for me.'

Some felt that you do it because you were used to it or because you don't know any different.

'It was difficult but you knew nothing different at that time.'

'I'd grown up with it. It was just kinda normal to me. I just did it.'

Other young carers expressed a clear dislike and resentment of having to provide care.

All the young carers and former young carers interviewed found the situation stressful and traumatic, to a greater or lesser extent.

You were constantly stressed to the limit. Terribly stressful; so I grew up in a terribly stressful situation.'

'I get fed-up sometimes.'

'Very stressful; you just want to run away sometimes. ... Everyone just wants to run away from it 'cos it's horrible like. You just want to get away from it.'

'Looking back it was absolutely atrocious; I don't know how we survived it. It was completely traumatic.'

'It's kinda annoying.'

Many expressed anger and hurt at the situation they had been placed in and at the fact that no one intervened to change that situation.

‘What hurts me most is the fact that all that went on and there was no one took any notice.’

‘When I came to sixteen, seventeen, eighteen, I felt very angry. Extremely angry [Her brothers and older sister took no responsibility.] and for years I really and truly resented their freedom, their lack of responsibility, lack of consideration for both of us.’

‘By the time I was sixteen I was completely angry, I was completely frustrated.’

Young carers were very upset by their situation or by seeing their relative, often their parent, feeling unwell.

‘Seeing her there, not well at all; you wouldn’t be able to put up with that every day, looking at her when she’s not well at all.’

‘I felt awful.’

Some young carers felt trapped by the situation of having to provide care:

‘You were in a cage and you couldn’t get out.’

3.5 Impact of Caring on Young Carers

This research has clearly demonstrated that being a young carer has a significant, and usually negative, impact on the lives of the young people involved. The impacts of caring at a young age are multidimensional, affecting education, physical and mental health, social life, career and life chances and choices.

3.5.1 Education

Being a young carer had a significant impact on the education of the young carers and former young carers interviewed.

For one of the former young carers, who was caring from when she was a toddler, being a young carer resulted in her missing out almost completely on education. Because of caring responsibilities the child was kept home from school from an early age, with significant implications for her education and life chances.

'You'd have a couple of days at school, days off from school – you'd have to stay at home if there was no one to look after them. Now I loved school. I wanted to be educated. It affected me all through life. Now I can't apply for a job or anything like that now 'cos I'm not educated enough.'

She is very angry that no-one intervened to ensure she received an education. Doctors, nurses, TDs and the school were all aware of her situation.

'And yet I went through the net, stopping at home from school and caring at home. And nobody ever came to say this can't go on, this child has got to go to school.'

There is an element of gender discrimination in this case. Her brother was educated but it was not considered as important that she be educated because she was a girl.

'And being a daughter, it was kinda seen in those days that a daughter, sure why would you bother educating her, she'd only be getting married. In those days it was nothing thought of a daughter. A son had to be educated but not a daughter. So I was the one.'

Her lack of education impacted on her throughout her life, affecting in particular her self-confidence and work opportunities.

'It has affected me now like if I'm applying for a job or talk up at meetings or things like that, I'm afraid of saying the wrong thing. I know it's all inside me what I want to say out but I'm afraid I'll say the wrong words, my grammar would be very bad. And if I was asked then to write a few words, comments, I'd fall down on that. That's how it's affected me all through my life. And there'd be different jobs come up and I couldn't take them.'

Being a young carer also impacted significantly on the education of another former young carer who was caring for her younger sister from when the sister was a baby and the young carer was nine years old. She would care for her sister before she went to school in the morning, feeding, changing and bathing her. She would then come home from school during the morning break at eleven to feed and change her sister and would come home again at lunch time, make the lunch and light the fire. Once school finished for the day she would come straight home, care for her sister, do the housework and make the dinner. This obviously impacted greatly on her ability to concentrate at school and to do her homework:

'I mean there wasn't time for schoolwork as such.'

Her father died when she was sixteen and she left school half way through her intermediate certificate year and went out to work. She returned to school later to do her leaving certificate but didn't do well as she had missed out on so much of her education at that stage. This then impacted on the kind of work she could do.

'I just worked in menial jobs all through the years.'

She had wanted to work with children with special needs but didn't do well enough in her leaving certificate to enter the training course. Her practical experience in providing care for her sister with special needs was not taken into account.

One of the other former young carers would have missed out on some school because of caring responsibilities.

'Certainly I would have missed days here and there and certainly would have, if we'd had a really bad time of it during the week I would have stayed out to care for my mother for sure.'

However, the greatest impact for this young carer was on her schoolwork and ability to concentrate and study.

'I simply could not study at all.'

She was doing well at school before her mother became ill and would have been in the honours class for most subjects. The stress of the home situation impacted on her and on her education.

'I would have changed and that would have been noticeable in school. I was quite angry the whole time. I didn't feel I could cope at all education-wise.'

She began missing out on school. She did sit the leaving certificate but wasn't able to concentrate and didn't do very well in her exams. She didn't feel able, at that stage, to go on to further education and instead began to work in factories. She was in her mid-20s before she returned to education.

'I would say that because of what happened, because of the lack of supports, both informally and professionally, it completely put my life on hold for at least a good seven to eight years.'

Caring responsibilities also impacted significantly on the educational experience of an eighteen-year-old carer who was caring for her mother and younger siblings since she was twelve. She missed out on lots of school: she would miss a few days each week and would sometimes be out of school for a few months at a time.

'I lost out, that was the main reason I never finished my leaving cert was 'cos I was always at home minding my sister. ... so I missed out so much at school that I never got to finish it. I missed out on lots of secondary school.'

She has now returned to education and is attending Youthreach, which she really enjoys.

'I love to come here in the morning. I'm the first up because it gets me out of the house for a few hours. ... Hopefully I'll get college or something out of it.'

A fifteen-year-old carer had been missing out on a lot of school, partly because of the situation at home.

'I usen't go to school at all. Because my mam was sick I thought I didn't have to go to school. I didn't bother going.'

He started to get into trouble, stealing motor bikes. His mother became very upset because he was missing school and getting into trouble. Given their close relationship, this affected him and he decided to go to Youthreach, where he is now studying for his junior certificate. He finds Youthreach to be a much more supportive environment than his previous school; they are understanding if he needs to come to school late because he is helping his mother:

'This place is grand.'

A fourteen-year-old carer avoided having to miss out on school because his father and older brothers took on a lot of the caring responsibilities at home. However, the stress of the situation at home, and in particular of trying to balance school work and caring responsibilities impacted on him and he began to get very bad headaches.

‘When I started secondary school I had nineteen subjects to do and come home and a load of homework and learning and then have to help Mum at the same time and you wouldn’t have time for everything like and it was just annoying. And I suppose that’s what brought them on.’

A twelve-year-old carer misses out on attending school sometimes, but is usually able to go to school. However, given his caring responsibilities when he comes home from school, he sometimes does not have enough time for his homework in the evenings. He goes to school early and does some of his homework then.

Similarly, a thirteen-year-old carer doesn’t miss out on school but does find it difficult to find enough time for homework. It is particularly stressful coming up to exam time at Christmas and the summer.

‘It’s hard trying to balance it all.’

This young woman’s mother often needs help during the night time.

‘I do the night time about three times a week. She keeps me up sometimes all night.’

As a result she is tired going to school and this impacts on her ability to concentrate on her schoolwork. She hasn’t explained her home situation to her teachers, who are therefore unaware of why she is tired in class.

'Cos they teach me stuff, they're your teachers – you don't actually tell them what's going on. They only teach you, they get paid for teaching you but not to hear what's going on.'

Being a young carer adversely affected the education of the young carers and former young carers interviewed. This ranged from completely missing out on education, to difficulties balancing homework and caring responsibilities. Most received little or no support from their schools and there was little intervention to ensure that their education was not affected. Missing out on education has had implications for their life and career choices.

It is positive to note, however, that two young carers' experience of education changed when they began to attend a Youthreach centre. Both are now enthusiastic about their education and have plans to continue with further education and training. This demonstrates how a more supportive and aware educational environment can mitigate the impact of caring on young carers' education.

3.5.2 Work/Career

It was clear from discussions with former young carers that being a young carer impacted significantly on their work and career paths. For most of them this was directly linked to the fact that their caring responsibilities had adversely affected their educational opportunities, as outlined above. This limited the range of employment opportunities open to them and many ended up in factory jobs or doing what one woman described as 'menial work'.

For some the impact on employment prospects has been felt right through their lives and continued to affect their confidence to apply for jobs.

'I've been offered different jobs since that are better paid but I feel I wouldn't be educated enough for it. It hits me all the time.'

You'd be knocked down all the time. You're being reminded all the time of what you missed out on.'

The former young carers feel that their career paths and life choices have been significantly affected by their caring responsibilities. As one woman put it:

'I would have probably taken different roads. There would have been different paths open to me.'

Most of the former young carers have ended up working in the field of caring. One woman has spent her whole life providing care for family members and subsequently working as a carer in a convent.

'So the caring role is still there; it will never leave me; it's there.'

One woman wanted to train to work with people with special needs but, because she had missed out on so much of her education, didn't have the right educational qualifications and her practical work experience in this area wasn't taken into account. So she continued to work in factories until recently. She now works as a home help where her years of caring experience are valued and she provides training for other home helps and works with 'high maintenance' patients.

Another woman went from school into factory work which she hated. She was in her twenties before she returned to education and trained as a social worker. She now works as a social worker in the psychiatric services. She feels that her own experience as a young carer gives her a greater insight and understanding of the issues faced by her clients.

'I think it gives me a deeper empathy with what the family are going through, with what certainly the younger members of the family are going through as well.'

Some of the current young carers have expressed interest in working in the field of caring. One young woman who has been caring for her younger siblings has expressed an interest in working in childcare, because she has practical experience in this area, or else training as a counsellor.

'Cos I feel that I was so messed up that I could help people who are messed up as well. And that would make me feel a lot better in myself to see, to try and help other people in the same situation. A few career choices out of it anyway!'

Another young carer wants to work in the medical field and feels that her experience in caring for her mother would be of benefit to her.

'Well I kind of want to do medicine when I'm older so I've kind of got a head start.'

3.5.3 Social Life/ Relationships

Most of the young carers and former young carers interviewed said that being a young carer impacted on their social lives and relationships. Because of their caring responsibilities they had less time to spend with friends, to develop relationships and to engage in social activities.

Young carers who missed out on lots of school because of their caring responsibilities also missed out on the opportunity to develop friendships with classmates.

'I had no school pals, 'cos the school pals I couldn't have.'

They also missed out on social aspects of school life, such as school outings.

'And it was so horrible then to find that even school outings, they'd be going away, that time they'd go up to the zoo in

Dublin, it was a great excursion, up to Dublin in the bus, it was fantastic. I couldn't go.'

One former young carer has been providing care since she was nine years old. Now in her thirties she has never had a relationship and she feels that this is directly a result of being a carer.

'I've never had time to get into a relationship because you couldn't go out, you didn't have babysitters and things like that. There was never any kind of a relationship. You couldn't. Being a carer is a very lonely experience.'

Some of the young carers resented the fact that they had little time to 'hang out' with their friends and that while their friends were out playing and having fun they had to stay home and help out.

'I don't hang around with my friends as much.'

'Most of my friends they'd be out nearly all the time and I have to stay in and help my mum. I'm not able to go out as much.'

'I went out for the first time in about a month Sunday and stayed overnight in a friend's house. That was the first time in about a month that I done that, went out for longer than a few hours.'

Some of the young carers and former young carers felt unable to invite friends to come to their homes because they were embarrassed about the situation at home or because their family didn't want anyone to know what was going on.

'There were no school pals to come to the house 'cos my father didn't want anyone.'

'I usually go to my friends' houses. I'm kind of embarrassed about the situation at home.'

'I wouldn't want my friends to come round here.'

For some young carers it was the constant interruptions which caused frustration. They would be in the middle of doing something, spending time with friends, being out, watching TV, etc., and would be called away to help out and provide care.

The lack of free time for their own activities also caused difficulties for young carers.

'Like as a carer you were always clock watching, always, always clock watching. You never ever had free time. You might get two hours, you know what I mean.'

'I don't have enough time to practise my piano, violin and flute.'

Any free time or social activities have to be planned and may have to be cancelled at short notice if circumstances change.

'I have to arrange weeks beforehand if I want to go out for a night or anything like.'

'Like I could say to you I'll meet you Friday night, eight o'clock, no bother. Seven o'clock I could ring you and have to cancel. So you lost a lot of friends because of things like that.'

3.5.4 Health (Mental and Physical)

Being a young carer can have a detrimental impact on the health (mental and physical) of the young people involved.

This can be most clearly seen in health problems that are directly related to or caused by the caring work. Examples of this include physical exhaustion and back problems.

‘I don’t like doing it. It hurts my back sometimes. And I pull my muscles a lot as well. My back, my arms and my legs.’

‘I’m exhausted from it.’

Other physical health problems can be linked to the stress associated with being a young carer.

One woman developed allergies, with associated health problems, which she feels was because she was in such a stressful situation at home.

‘My health was deteriorating; I had a lot of allergy problems, but that time they didn’t know it was allergy problems. I was getting sick a lot, then the doctors, and in and out of hospitals; they didn’t know what was wrong with me. Stress, my system had broken down.’

One young boy began to get really bad headaches, which had no apparent physical cause. The doctor advised him to visit a counsellor who linked the headaches to the stress the boy experienced in trying to combine his caring responsibilities with a heavy school workload. Strategies to address this stress have succeeded in relieving the headaches.

For many young carers the greatest impact is on their emotional and mental health. The majority of the young carers and former young carers interviewed experienced stress because of their situation. For some this led to depression and anxiety. Some former young carers have needed to go to a counsellor to deal with the impact of this stress on their emotional and mental health and some of the current young carers felt that they needed to see a counsellor to help them deal with their current situation.

‘Looking back I would say most certainly my older brother and myself, I would say certainly our mental health suffered. And I would say that we became depressed for quite some time.’

‘Emotionally you get very depressed when it gets like this, ’cos you don’t know what to do or you feel like nobody’s there for you to help or anything.’

‘Not knowing what’s going to happen next. Constantly worrying about everything. And not having a life basically.’

3.5.5 Poverty

Many of the young carers and former young carers interviewed had to deal with financial hardship directly linked to their position as young carers.

For some this was because they were living alone with a parent who was unable to work because of illness or disability and the family was subsequently dependent on social welfare payments.

‘We were completely pauperised through all this as well.’

‘Money was very, very tight.’

In one situation the young carer was caring for an ill parent and, when the situation worsened, the second parent had to give up work to help care for the ill parent. This had subsequent implications for the family’s financial position.

Another young carer had to leave school and to go to work to support her family because her father died when she was sixteen.

‘Yeah, there was no money. There was a widows and orphans pension, ’twas £23.50. Going back then that wasn’t an awful lot

of money. I think we were a pound over the poverty line. That meant you got no benefits.'

'There were days when we barely had food. There were days when we had to burn shoes, we didn't have coal.'

In one particularly disturbing case, the current young carer and her siblings are occasionally in a position where they would have no food or money. Their mother suffers from manic depression and when she is 'high' she takes the family's money and leaves nothing for the children.

'Cos when my mother gets like this she takes any money that we get and basically spends it on cigarettes and nothing else really. So there'd be no food or anything.'

'I remember around two years ago she got sick and my little sister was taken out of it, she went to stay with my aunt. And there was me and my brother in the house for about a week by ourselves with no food or nothing. So that was horrible.'

When asked what kind of supports would help to make her situation better her answer was:

'Financial really, because she takes money, and coal and stuff like that. It's just food basically and heating that is sometimes needed.'

However, the financial hardship and impoverishment is just one aspect of the poverty implications for young carers. It is clear from this study that being a young carer leads to impoverishment of young people's lives. This can be seen in the impact on their educational opportunities, reduced life choices and impact on their future employment options and earning potential. Being a young carer also leads to impoverishment in terms of young people's social lives, relationships and interaction with peers.

3.6 Information, Professional Intervention and Supports

One of the biggest problems identified by the young carers and former young carers in this study is the lack of information and of professional interventions and supports for the young people.

Many of the young carers and former young carers mentioned that they didn't understand what was going on when their parent became ill and that nobody explained the situation to them. This was very confusing and frightening, particularly when they were so young.

'Here at home we didn't know what was wrong.'

'When I was a young carer, there was no information; there was no access; like we never saw a social worker. I know it's changed today but we never saw a social worker. We saw nobody. Not a public health nurse, nothing.'

'Looking back now, we would have gone, What the hell is this? We wouldn't have understood it. I was 15; my brother would have been 17. We didn't know what it was. We weren't really approached by anybody. We weren't really visited by a community psychiatric nurse or anything like that, not that I can remember at all. And then the contact with the hospital would have been between the hospital and my father or my mother's brother; they would have been the people that the situation was discussed with.'

Former young carers expressed anger that, even though professionals such as doctors, teachers or social workers would have been aware of their situation, nobody had intervened to assist the young people.

'What hurts me most is the fact that all that went on and there was no one took any notice.'

'I distinctly remember going up to the GP for her sick form. And she would be in terrible condition. And the GP would just hand out the sick form and never visit us or discuss anything with us.'

'It was an absolute disgrace what was going on in the sense of us not being approached, supports not being put in for us.'

Discussions with current young carers show that there is still inadequate professional intervention and supports for young carers. For example, one young carer who is caring for a young sibling because of her mother's mental illness has stated that she receives no professional support, receives inadequate information and intervention from her mother's doctor and has never been contacted by a social worker.

However, one of the other current young carers spoke of the difference that an engaged and supportive social worker had made to his family. She engages with the son as well as the mother and provides practical supports for the family.

'The social worker is brilliant like.'

'She comes around a lot and helps out with stuff to do with the house, like the chairs and carpets. She'd be up the whole time. She and my mam talking and having a cup of tea. You wouldn't think she was a social worker at all, you'd think she was one of my mam's friends.'

Both current and former young carers stressed the need for more adequate Home Help and Respite Care and expressed anger at the recent cutbacks in these services.

In addition to the lack of adequate professional supports, some former young carers were angry at the lack of support and help from family members and at the fact that they were left with all the caring responsibilities.

'I suppose when I came to sixteen, seventeen, eighteen, I felt very angry. Extremely angry. 'Cos I've three brothers and I've one older sister. The older sister was gone, she was in America, so she was gone. The three boys never ever took responsibility.'

'For years I was very angry that they weren't doing their bit like.'

However, for some of the current young carers, their situation is somewhat relieved by assistance from family members, including the other parent, siblings, or aunts/uncles.

3.7 Contact with Other Young Carers

Isolation can be a major problem for young carers. Because of their caring responsibilities they often have less time to spend with their friends and peers. Young carers also felt that it could be difficult for friends to understand what it was like to be a young carer and some felt too embarrassed to discuss their home circumstances with their friends.

Few of the young carers knew of, or had contact with, other young carers and they often felt that they were the only one in that situation.

Two of the young carers had participated in an event for young carers which was organised by the Cork MS Society. They found it beneficial to learn that there were other young carers and that they shared similar experiences.

'I actually didn't realise that there were others. I thought that there'd only be a few others but there was a good few.'

‘It was good to talk to them. You wouldn’t know about it – you’d think you were the only one.’

Most of the current young carers expressed interest in meeting with other young carers and in participating in a Young Carers’ Group if one were established. The prime motivation was to combat their sense of isolation and to be able to talk with other young carers who would understand their experiences.

‘Someone to talk with that they know what you’re dealing with and we know what they’re dealing with.’

‘We could share problems and you wouldn’t feel so isolated.’

‘Doing this you feel very alone. You feel that there’s nobody else around. So it would be nice to find out how other people deal with it and stuff. I think that (a young carers’ group) would be a very good idea alright.’

3.8 Conclusion

It is clear that being a young carer has significant implications for the lives and wellbeing of the young people involved. The areas affected include education, employment, social life, relationships and health, and smooth transitions to adulthood.

Being a young carer can lead to impoverishment of young people’s lives, not only in terms of financial hardship and lack of basic resources such as food and heating, but also in terms of the impoverishment of their lives, affecting their education and employment opportunities, their social lives and interactions and their health.

The lack of adequate information, supports and professional interventions has exacerbated already difficult situations for young carers. It is clear that

adequate professional supports and interventions are essential in mediating the impact of caring on young people's lives.

4 Conclusions and Recommendations

Conclusions

This research was an exploratory study which set out to give a voice to hidden young carers who are largely unseen and unrecognised both within the enumerated care givers of the population and within the population of the country as a whole. This research can be seen as a first step in remedying that situation through giving them a voice to articulate their attitudes and experiences, and the short-term and long-term impacts of their caring responsibilities. A number of important conclusions emerge from the research.

4.1 Implications for Lives and Wellbeing of Young Carers

The interviews revealed that caring responsibilities bring significant implications for the lives and wellbeing of the young people involved. The areas affected as identified in the interviews include education, employment, social life, relationships and health. These findings are largely consistent with the international research discussed in Chapter two, though as already noted US research suggests an absence of adverse emotional or mental health impacts of young caring in adulthood.

4.2 Risk of Poverty and Social Exclusion

This research has revealed that being a young carer can lead to the impoverishment of young people's lives, not only in terms of financial hardship and lack of basic resources such as food and heating, but also in terms of reducing their life chances, by affecting their education and employment opportunities, their social lives and interactions with their peers and their mental and physical health.

4.3 Absence of Professional Supports

Interviewees highlighted the lack of adequate information, supports and professional interventions which exacerbate already difficult situations for young carers. It is clear that adequate professional supports and interventions are essential in mediating the impact of caring on young people's lives (as discussed below).

4.4 Awareness of Health, Social Care and Education Providers

Service providers when informed of the research findings reported a low level of knowledge or understanding of the experience of hidden young carers. A greater level of awareness of the needs of young carers on the part of professionals such as social workers, youth workers, community development workers, health professionals, home-school community liaison officers, etc., is essential to help in early identification and in devising appropriate responses. Extension to the remit of particular services such as the carers support office of the HSE (South), and, subject to adequate resources, the Carers Association, should be considered as a priority. For other organisations working with families where young carers may exist, strategies for heightened awareness of their needs should be devised.

The interruptions/ dilution of formal educational experiences caused by caring responsibilities places hidden young carers at a considerable disadvantage in terms of life chances, labour market participation or acquisition of formal qualifications. Nonetheless, this research has revealed that despite the adversities they endure young carers build up significant skills and resources in taking on care responsibilities. In this regard consideration should be given to policy initiatives aimed at giving recognition to the experiences and skills of young carers such as VEC-certified training initiatives, the EU Leonardo programme, distance learning programmes, etc. Such initiatives would mirror proposals for recognition and accreditation of the adult caring role made in recent policy documents such as the *NAP Social Inclusion*.

Recommendations

4.5 Policy Responses

It is evident from this the? literature and policy review that official awareness levels of the existence, contribution, needs and experiences of hidden young carers in Ireland is uneven. Policies and strategies (both statutory and non-statutory) have to date not adequately acknowledged the existence of, or roles fulfilled by hidden young carers.

As a first step in redressing this omission, future policy documents, including most immediately the proposed national carers strategy, should overtly acknowledge the existence of, and contribution made by young carers and highlight the necessity for policy and support measures to meet their needs. Having said that, policy responses to the negative impacts identified in the research must be carefully considered. Service providers consulted during this research, and echoing the international literature, pointed out that special initiatives, while welcome, must be sensitive to the dangers (of isolation, stigmatisation and tokenism) attendant on targeted interventions. The burden on young carers is bound up with the absence of, or lack of access to services and supports for those cared for. Responding to the needs of young carers should ideally focus on the needs of all family members within a wider community context. To this end consideration should be given to the negotiation, with their consent and participation, of a care plan for all young carers. This should be devised on a consultative basis by the relevant statutory agencies and should clearly stipulate the roles and responsibilities arising for them.

4.6 Institutional Framework

The dissemination of the interview findings through the seminar and the audit of service providers highlighted a high degree of commitment to respond to the needs of hidden young carers. In building on this commitment, as an initial measure, consideration should be given to the establishment of consultative committees to promote awareness and determine appropriate policy responses in their area.

4.7 Further Research at National Level

In light of the issues raised by hidden young carers in this research further investigation of their experiences is warranted. Consideration should be given to a larger-scale (possibly national-level) study aimed at enumerating in quantitative terms the number of young carers and the extent of hidden caring carried out by this difficult-to-access population. This would enable the development of an appropriately scaled support infrastructure for young carers which could be used as the basis for national frameworks of

recognition, policy and support measures and interventions such as individual care plans.

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Appendix 1: Survey audit of relevant organisations whose brief may include providing services to young persons who have assumed caring responsibilities

Purpose of the audit

The audit of service providers was undertaken to ascertain the degree of awareness and extent of recognition in policy and service provision within a range of statutory and voluntary organisations. Organisations were requested to respond to a series of questions by postal survey as listed below.

Response rate

A total of seven organisations responded to the survey, comprising three statutory bodies and four voluntary/community bodies. The statutory bodies were: The National Education Welfare Board (NEWB), the Health Service Executive South (HSE formerly the Southern Health Board), and the County Cork Vocational Educational Committee (VEC). The voluntary/community bodies were: Multiple Sclerosis Ireland (MS Ireland), People With Disability Ireland (PWDI), the Irish Society for the Prevention of Cruelty to Children (ISPCC) and the Carers Association of Ireland.

Profile of audit respondents

- National Education Welfare Board: A statutory body dealing with school attendance (NEWB)
- Multiple Sclerosis Ireland: A voluntary association offering support to persons with M.S. and their families
- People With Disability Ireland: A community-based organisation which campaigns for services and provision for people with a disability
- Irish Society for the Prevention of Cruelty to Children: A voluntary organisation which provides family support and child welfare services

- The Health Service Executive (South): A statutory body responsible for the provision of health and a range of personal and family support services
- The County Cork Vocational Educational Committee: A statutory body which provides educational services throughout Cork county
- The Carers Association: A national voluntary organisation which lobbies on behalf of carers and provides support to persons with caring responsibilities.

Themes included in the audit

1. Awareness of existence and circumstances of young carers
2. Mention of young carers in the organisation's policies and documents
3. Existence of services specifically targeted at young carers
4. Inclusion of young carers in any services currently provided for carers
5. Plans to develop policies, initiatives or services for young carers
6. Whether any current policies or initiatives be adapted to meet the needs of young carers
7. Initial response to young carer interview findings.

Audit Questionnaire

1. Would it be accurate to say that there is currently little or no awareness within the (name of organisations) of the existence and circumstances of young carers in the Greater Cork Area?

Yes

No

(please circle)

If 'No' please give examples to support this answer.

2. Would it be accurate to say that there is no mention of young carers in any current (name of organisation) policies or guidelines with which you are familiar? Yes No *(please circle)*

If 'No' please give examples to support this answer.

3. Does the (name of organisation) currently have any services which are targeted specifically at young carers?

Please give details and enclose any relevant documentation.

4. Are young carers included in any services currently provided for carers?

Please give details and enclose any relevant documentation.

5. Does the (name of organisation) have any plans to develop policies, initiatives or services for young carers?

Please give details and enclose any relevant documentation.

6. Could any current (name of organisation) policies or initiatives be adapted to meet the needs of young carers?

Please give details and enclose any relevant documentation.

7. Please provide a (name of organisation) response to the issues raised in the Report on Young Carers attached.

Summary of Audit Findings

Table A1.1: Organisations were asked to indicate whether they had an awareness of existence and circumstance of young carers

Respondent	No	yes
NEWB	X	
MS Ireland		X
PWDI		X
ISPCC		X
Co. Cork VEC		X
Carers Association		X
Southern Health Board (HSE)		X

Comments made by organisations surveyed in response to the question:

MS Ireland: Notes that their 1996 report mentions young carers; their casework service works with young carers, 'which informs the organisation of young carers'.

PWDI: 'As a cross disability support organisation the Cork Network of PWDI is well aware of the inadequacies and levels of care.'

ISPCC: 'An ISPCC intervention with children and families is conducted in the family home. It involves a period of assessment where such factors are taken into consideration.'

VEC: Refers to provision of certification and courses for carers by Co. Cork VEC

Carers Association: Provides respite to a young carer looking after his father; intend to run Schools Information programmes to raise awareness of general caring.

Table A1.2: Organisations were asked whether there was any mention of young carers in the organisation’s policies and documents

Respondent	No	yes
NEWB	X	
MS Ireland		X
PWDI		X (see below)
ISPCC		X (but only generally)
Co. Cork VEC		X (but only generally)
Carers Association		X
Southern Health Board (HSE)		X

Comments made by organisations in response to the question

MS Ireland: The MS Ireland Strategic Plan p. 15 refers to special consideration needing to be given to ‘child carers’.

PWDI: States that ‘improving the level of care of people with disabilities is a fundamental objective of PWDI’ and gives example of last AGM.

ISPCC: ‘While it’s not within a specific policy document, factors such as children’s rights are mentioned in all our policy documents.’

Co. Cork VEC: ‘Included in adult education courses [childcare courses – Carers (Adult and Young) in Strategic Development Plan] and in programmes and mission statements.’

Table A1.3: Organisations were asked to indicate the existence of services specifically targeted at young carers

Respondent	Yes	no
NEWB		X
MS Ireland	X	
PWDI		X ('nothing specific')
ISPCC		X ('not specifically')
Co. Cork VEC		X (not specifically, see Table 2)
Carers Association		X (but see details)

Comments made by organisations in response to the question

MS Ireland: States that caseworkers are available to work with young carers; also that a counselling service is available. A young carers' support meeting is planned with facilitator/counsellor input.

ISPSS: Services not specifically offered, 'but should a young carer approach the ISPCC or be referred' they would work with the young carer and their family.

Co. Cork VEC: 'See above.'

Carers Association: 'Not specific to young carers but they get special focus when they are involved.'

Table A1.4: Organisations were to indicate whether young carers are included in any services currently provided for carers

Respondent	Yes	no
NEWB		X (n/a)
MS Ireland	X	
PWDI		X (unspecific response)
ISPCC		X
Co. Cork VEC	X	
Carers Association	X	

Comments made by organisations in response to the question

MS Ireland: See Table 3

Co. Cork VEC: ‘Carers courses are open to all age groups.’

Carers Association: ‘Respite is the main area where young carers get special attention when we receive information about them as carers; no documentation regarding respite.’

Table A1.5: Organisations were asked to indicate whether they had plans to develop policies, initiatives or services for young carers

Respondent	Yes	no
NEWB	X	
MS Ireland	X	
PWDI		X (only indirectly)
ISPCC	N/a	
Co. Cork VEC		X (only indirectly)
Carers Association		X

Comments made by organisations in response to the question

NEWB: Section 17.2 (g) of the Education Welfare Act 2000 states that there may be ‘sufficient cause’ for a young person’s non-attendance at school. ‘The NEWB will advance and assist in such cases.’

MS: See Table 3.

ISPCC: ‘All services are directed at 0–18 target group.’

Co. Cork VEC: Ongoing – strategic plans.

Carers Association: Formerly had certain initiatives, but it seems that there was poor involvement by young carers.

Table A1.6: Organisations were asked to indicate whether any current policies or initiatives could be adapted to meet the needs of young carers

Respondent	Yes	no
MS Ireland	X (indirectly)	
PWDI		
ISPCC	X	
Co. Cork VEC	-	-
Carers Association	X	
Southern Health Board (HSE)	X	

Comments made by organisations in response to the question

MS Ireland: ‘Young carers being considered as part of ongoing service and future developments.’

ISPCC: Mentoring programmes, CSW service, children’s consultation.

Co. Cork VEC: ‘N/a, ongoing.’

Southern Health Board (HSE) “The recently published Action Plan for the Development of Physical and Sensory Disability Services: “Supporting an Independent Future” makes reference to the need to co-ordinate services for carers in the statutory and non-statutory sectors.”

Table A1.7: Organisations were asked to offer an initial response to young carer interview findings

Respondent	Yes (responded)	No (did not respond)
NEWB	X	
MS Ireland	X	
PWDI		X
ISPCC		X
Co. Cork VEC		X
Carers Association	X	

Comments made by organisations in response to the question

NEWB: Notes that the interview findings ‘highlights the lack of open communication between young carers and the school around homework and the inability to concentrate because of the stressful home situation.’

MS Ireland: Sees particular relevance to the organisation and development of their services in the areas of information, support and intervention.

Carers Association: Would like to get more involved in young carer-specific projects, but cite lack of resources, particularly personnel, as obstacles to doing so.

Overall commentary on findings from audit

The responses from the different organisations illustrate the difficulty of isolating young carer issues from other issues and interventions, e.g. in relation to child welfare generally or to problems of adults with care needs, and of issues around these. One might suspect that young carers who attend VEC courses or are offered respite are in fact at the upper end of the young carers age range. Organisations articulated differing views on the desirability of whether to recognise young carers as a specific category of the caring population especially in regard to how this may create difficulties with statutory obligations around child protection and welfare and school attendance. Many hidden young carers come from families which are already vulnerable and for that reason wish to remain hidden and avoid drawing official attention to their situations. There was a consensus amongst organisations surveyed that interventions from statutory and other social care agencies must therefore be very carefully nuanced and based first and foremost on the principal of improving the welfare of the young carers and their families. Unless this is adhered to well intentioned interventions may well be negative and counterproductive in their effects and lead to further marginalisation of young carers and their families.

Appendix 2: Seminar on Young Carers

The second stage of the research on young carers entailed the facilitation of a day-long workshop aimed at individuals and organisations whose services have a bearing on young people who fulfil caring responsibilities.

Purpose of the seminar

A core objective was to impart the findings of the young carer interviews to the seminar. Additional aims of the workshop were:

- To assess the levels of awareness of the existence of young carers and their specific needs among statutory, voluntary and community organisations working in the area of health, community development, education and social services
- To determine the extent to which agencies made specific provision in response to the needs of young carers
- To disseminate the findings of the interviews with young carers on their experiences and needs
- To identify what strategies at a policy level and service delivery level could be adopted to better respond to the needs of young carers.

On the basis of the main issues arising from the interviews with young carers the seminar was structured around a number of key themes: life chances, community development, and education. Workshop participants were assigned to a thematic area related to the nature of their organisation and the service it provided.

Table A2.1 Profile of Seminar Participants

	Name of Organisation	Nature of Service Offered	No. of Staff attending Seminar	Specific Provision of Services for Young Carers
1.	HSE (South)	Health and Social Services	11	No
	HSE (South) Support for Carers Office	Co-ordination of services to carers in SHB region	1	No
2.	Multiple Sclerosis Ireland	Services and Support of M.S. sufferers	1	No
3.	National Education Welfare Board	School Attendance Services	1	No
4.	Department of Education and Science Home School Liaison Officer	Promoting cooperation between home, school/community agencies	1	No
5.	Cork City Partnership	Local and Community Development Services	3	No
6.	Gurraneabraher Youth Centre	Provision of Services to Young People	1	No
7.	Cork Rapid Programme	Revitalisation of designated disadvantaged areas	1	No
8.	Irish Society for the Prevention of Cruelty to Children	Childcare Support Services	1	No
9.	Department of Social and Family Affairs	Provision of social welfare services, payments and support	1	No
10.	Local Employment Service	Co-ordination of Local Employment Services	1	No
11.	Cork City Development Board	Communities involvement in provision of public services	1	No

12.	The Carers Association	Support and Advocacy for Carers	1	No
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Seminar Feedback and Recommendations

Acknowledging the existence and role of young carers

There was a general consensus that the existence of young carers is largely unacknowledged by service providers and their needs go unrecognised within policy and support services for carers in general. Of the 12 organisations/ service providers represented at the seminar none made specific provision for young carers in their policy brief or service provision. (See Table 1 below.)

Validation of findings and commitment to respond

Despite the absence of a specific awareness of the existence of or needs of young carers there was a high degree of validation of the experiences of young carers as revealed by the interview findings. Service providers previously unaware of the extent and impact of young carers were highly disposed to responding to their needs, once the experiences revealed by the research were highlighted.

Source of non-recognition: Invisibility rather than exclusion

On the basis of the seminar presentation of the research findings and the follow-up workshops it can be understood therefore that the lack of recognition of young carers and their needs has arisen out of their invisibility rather than their active exclusion by service organisations and providers.

Variety of contexts within which young carers operate

A broad consensus among service providers was that hidden young carers exist in a wide variety of contexts. It was noted that the roles of young carers can range from responsibilities that could be classed as a normal and proportionate contribution to their family/households and do not place them at a major disadvantage, to those that are excessive and disproportionate

and can result in young carers missing out on key areas such as education, contact with peers, etc.

Responding according to young carers' needs and circumstances

There was a consensus among service providers and participants at the workshop that while recognition of the needs of young carers was essential, such needs must be responded to in an appropriate way. Because of their caring responsibilities many young carers feel the necessity to remain hidden, for example to explain absences from school using excuses other than their caring responsibilities, or not to participate in youth clubs and sports because they feel unable to make a commitment.

Accordingly, responding to their needs should avoid further isolation of young carers as a separate category treated differently to their peers. Instead, the onus should be on service providers to adapt and adjust their interventions and responses at a more general level so that hidden young carers are not by virtue of their circumstances prevented from availing of services or participating in activities with their peers. In essence, service providers should work on the basis that there will always be a proportion of young people who are carrying caring responsibilities and services should be structured and delivered accordingly. 'Dangers of targeting and compartmentalising young carers as yet another "club" may lead to isolation' (Workshop participant).

Recognition of young carers in overall carers services

Workshop participants also felt, however, that existing support services for carers in general (as distinct from general service providers referred to in the previous paragraph) should acknowledge young carers in more specific terms. For instance in the HSE South Region there is a Carers Co-ordinator who currently has no mandate for young persons who carry caring out caring responsibilities.

Appendix 3: Interview Schedule for Young Carers

YOUNG CARERS RESEARCH

INTERVIEW QUESTIONS/ISSUES TO BE DISCUSSED

Preliminary: Explanation of project. Confidentiality. Feedback/ possible outcomes.

Name:

How old are you?

Where do you live?

Who do you live with?

Tell me about your family.

Do you get on well with them?

Tell me what it's like taking care of _____.

What do you do?

Is it every day/week (indication of extent of caring responsibilities)

How do you feel about taking care of _____?

What do you like about it?

What do you hate about it?

How does it affect you?

Do you ever feel stressed because of your responsibilities at home?

What do you think you learn from taking care of _____?

What things have you learnt to do?

Do you think you could use these skills in other ways, maybe for a job?

Where do you go to school?

Do you ever miss out on school because of responsibilities at home?

Is your school aware of your home situation?

Do they offer any support?

Tell me about your friends – who do you hang out with?

What kinds of things do you do together?

Do you go out often?

How do your friends react to your caring responsibilities at home?

Do you have any hobbies?

Are you involved in any groups or do you play sport?

Do you have much contact with other family members who are not living with you, e.g. grandparents, aunts etc.

Do they ever help out?

Who would you turn to for support if there was a problem at home?

Do you or your family have much contact with social workers, medical professionals, etc?

What kinds of help do they offer?

What kinds of things would make life easier for you and for your family – supports, services?

Do you know any other young people who take care of someone at home?

Would you like to have more contact with other young carers?

What are your plans for the future?

What would you like to do?

What would make this possible?

What do you think of the term 'young carer'?

Would you call yourself a 'carer'?