



*“If I can make their life a little  
easier, then I’m happy.”*



# Study of Young Carers in the Irish Population

## MAIN REPORT

The National Children's  
Strategy Research Series

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a little easier, then  
I’m happy.”*

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## **MAIN REPORT**

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# Acronyms used

AACY	American Association of Caregiving Youth
ABI	Acquired Brain Injury
CEOs	Chief Executive Officers
CFRC	Child and Family Research Centre
CRC	UN Convention on the Rights of the Child
HSE	Health Service Executive
MS	Multiple Sclerosis
NUI Galway	National University of Ireland, Galway
OMCYA	Office of the Minister for Children and Youth Affairs
SCIE	Social Care Institute for Excellence
YCRG	Young Carers Research Group



# 1 INTRODUCTION

## Overview

The term 'young carers' refers to children and young people under the age of 18 whose lives are affected in some significant way by the care needs of another family or household member, and who provide care, or help to provide care, to that person. (The full working definition of 'young carers' adopted for the purpose of this study is given in Chapters 2 and 3.) Traditionally, the focus of carer-orientated policy has been on adult carers. However, in the last 15 years there has been growing awareness of and interest in young carers. Research on this topic has greatly expanded and policy-makers and service providers are increasingly acknowledging the need for a specific policy response to address the needs of young carers and to provide support to them.

From a policy and service provision perspective, the issue of young carers is important for at least two reasons. First, it may be that a child or young person is providing the care that otherwise could, and should, be supplied by a welfare service provider, whether in whole or in part. Second, young carers themselves may be in need of services and this may be as a direct result of their caring responsibilities. The services and supports needed by young carers will differ, reflecting the variety and complexity of caring situations in the Irish population, and recognising this is central to any consideration of the services and supports required by young carers.

The growing awareness of and interest in young carers gives rise to a number of key issues:

- the definition of young carers;
- the impacts, both positive and negative, of caring on a child or a young person;
- the 'invisibility' of young carers and mechanisms that can be used to identify them;
- the services that are, or should be, provided to young carers.

The question may be asked, what differentiates 'young carers' from other children and young people? Even a 'normal' childhood involves mutual, reciprocal relations of caring among siblings and within the household. At the same time, the situation of young carers differs from the 'normal' experiences of childhood and youth in that the lives of young carers are affected in some significant way by the care needs of another family member and they take on responsibilities usually associated with adult life (Gray *et al*, 2008, p. 169). Nonetheless, the experiences of young carers are quite varied, differing with regard to levels of responsibility, the hours spent caring, the types of tasks performed, who they care for and the reasons why care is needed.

The fact that children and young people are taking on caring responsibilities draws attention in large part because of the potential negative impacts on the young carers. At the same time, some of the impacts can be positive. There is significant and ongoing disagreement among researchers, service providers and policy-makers about the impacts of caring on young carers. It is for that reason all the more important to give young carers a voice and to record their own perceptions of the impact of caring on their lives, as has been attempted in this study.

Research on young carers must address what is sometimes referred to as the 'invisibility' of young carers (Thomas *et al*, 2003). The children and young people, their parents and professionals working with the family often either do not perceive the children and young people to be 'carers' or else they do not want to bring attention to the situation. As a result, the role of young carers can very often be hidden. It is for this reason that one of the core research questions underpinning this study is to examine mechanisms through which young carers in the Irish population can be identified.

A further issue is what supports and services should be provided to young carers. Although policies and services have been developed for adult informal carers in the Irish population (Comhairle, 2002), the same is not the case for young carers. Young carers can often benefit indirectly from services received by the person in need of care, but they may require services designed to meet their own needs and to meet their needs as 'carers'. Finally, while young carers provide informal support within the household, they themselves can also be supported by informal networks of family and friends. Such networks of support may be considered a crucial part of the policy response to young carers.

## Previous research

There have been many important and insightful studies on young carers. The most significant of these were conducted in the UK, Australia, New Zealand and the USA, along with some relevant studies in the Irish context. These studies will be looked at in greater depth in the literature review (see Chapter 2).

In Ireland, there have been a number of studies concerning the impact on the family of a person with a disability, illness or addiction, or of bereavement and family breakup, and some of these findings are relevant to research on young carers. However, Irish research on young carers themselves is still at an early stage, thus presenting a significant challenge to developing an effective policy response. The present research is the first national qualitative study of young carers in Ireland. While it is both exploratory and preliminary, it does nevertheless provide an insight into the lives of children and young people who provide care in the home and uncovers the reality of their situation. The findings corroborate international findings in relation to young carers elsewhere (Aldridge, 2008; Butler and Astbury, 2005; Dearden and Becker, 2004; Roche and Tucker, 2003) and represents, therefore, a significant starting point for Irish policy, service and research in this area.

In the UK, the Young Carers Research Group (YCRG) at Loughborough University managed to conduct large-scale surveys of young carers. The samples were drawn from 'young carers projects' across the nation, which provide services to and represent the interests of young carers (Dearden and Becker, 2004). Although no such study has been conducted in Ireland, there is some quantitative data available from Irish census figures (CSO, 2004 and 2007). Also, although caution is called for in doing so, it is possible to draw some inferences about the situation in Ireland from findings about young carers elsewhere. However, in Ireland there is no organisation available on a nationwide basis for young carers, like the 'young carers projects' in the UK. This has important implications for research into young carers: (1) it becomes more difficult to estimate the prevalence of young carers in the Irish context, the types of activities they undertake as young carers, the impacts of caring and the provision of services to them; and (2) mechanisms for identifying young carers, along with their recruitment for a study such as this, itself becomes a central concern and theme of research in this area.

## Background to this study

The Office of the Minister for Children and Youth Affairs (OMCYA) commissioned this study in September 2008. In the Framework Social Partnership Agreement 2006-2015, *Towards 2016* (Department of the Taoiseach, 2006), the Irish Government committed itself to study the extent to which children undertake 'inappropriate care roles' and to establish the extent and degree to which this issue arises and the levels of impact it has on the lives of the children concerned. The Government's approach was two-fold: (1) it requested the Central Statistics Office (CSO) to undertake additional analysis on the 15-17 year-old children identified in the 2006 Census as carers; and (2) it commissioned this study through the OMCYA.

Of particular interest to the OMCYA (2008) in its Request for Tender was 'inappropriate' care. According to the OMCYA, the responsibilities of such young carers may include, from a young age, personal or intimate care, emotional support, help with mobility, domestic tasks and helping to look after younger siblings. It is believed that young carers differ from other children in terms of the extent of their caring, its nature, the time involved and the outcomes for their development and their social and economic participation. The Request for Tender also noted that, even where the development of services for young carers is advanced, as in the UK, there are still low levels of access to those services. What is more, young carers are, it is argued, a largely hidden group within society and this commissioned study was asked to look at 'mechanisms to empower these young people to come forward to avail of services'.

## Research aims and objectives

The OMCYA's Request for Tender clearly spelled out the objectives of this research and the core questions to be addressed. The specified aims of the research were:

- to examine mechanisms through which young carers (aged 5-17 years) in the Irish population can be identified;
- to explore the impact of caring on their lives;
- to identify ways in which they can be assisted.

To meet these aims, the study had 5 objectives:

1. To provide a comprehensive review of the national and international literature on children as carers, including definitions, legislation, policy and service provision.
2. To collate information about potential mechanisms that have been or currently are, or could be, used to identify young carers.
3. To examine the extent to which these mechanisms are effective in identifying young carers.
4. To recruit a sample of young carers and undertake empirical work with them on:
  - ways in which other young carers might be identified by the statutory and non-statutory sectors;
  - the extent to which caring impacts on their lives;
  - ways in which young carers could be assisted.
5. To make recommendations for the development of services for young people in situations of caring.

*Chapter 2* of this report provides a comprehensive overview of the national and international literature on young carers. *Chapter 3* outlines the methodological choices, challenges and solutions in recruiting a sample of young carers and agency staff from the statutory and non-statutory sectors and undertaking empirical work with them; it also highlights the study's findings with regard to potential recruitment mechanisms to identify young carers. *Chapter 4* documents the findings from the empirical work carried out with young carers, while *Chapter 5* sets out the findings from the empirical work undertaken with agency staff. *Chapter 6* discusses the study's findings. *Chapter 7* presents some conclusions and *Chapter 8* offers 'areas for consideration' in policy and services for young carers arising from the findings of the study.

# 2 LITERATURE REVIEW

## Context

For many years, there was little interest worldwide in issues relating to young carers. During the last 15 years, however, there has been a significant expansion of awareness with regard to issues facing children under the age of 18 who provide, or help to provide, care within the home. This growth in research interest, on an international scale, has been accompanied by a heightened political awareness of children and young people who provide care to a family member, with much policy being informed by the outcomes of empirical studies on young carers. What is more, important lessons can be learnt from previous studies, in particular concerning the recruitment of participants, methods of data collection and analysis, and the conceptualisation of 'young carers'.

However, when compared with the volume of research coming from the UK and Australia in particular, and despite important work in this area by Irish researchers, there is a dearth of studies focusing on the situation of young carers in Ireland. There is therefore much that needs to be known about this particular group. The present research seeks to address this knowledge gap directly, with the following literature review as a necessary first step in the process of better understanding young carers in the Irish population.

The aim of this chapter is to provide a comprehensive and current review of the national and international literature on young carers. This is vital in order to develop a conceptualisation of the role of young carers in Ireland, to examine mechanisms to identify these individuals and to move towards developing a working methodology, with practical guidance, for undertaking this original research. In addition, a review is provided of the national and international law, policy and service provision in respect of young carers, in particular to better identify ways in which they can be supported and assisted.

The methodology chosen for this review is first outlined; then current national and international law, policy and practice are examined, and the phenomenon of informal care is discussed. This is followed by an exploration of a number of specific debates and themes related to the issue of young carers, covering:

- the debate over children's rights;
- definitions of 'young carers';
- consideration of how children and young people become carers;
- awareness of the variability of care experiences;
- what young carers do;
- further issues arising from usage of the concept 'young carers';
- the 'invisibility' of young carers;
- the potential impact of caring on carers;
- age-inappropriate care;
- the relationships between caring, health and poverty.

The chapter closes with a consideration of the learning points from the literature for research in this area.

## Methodology

This literature review has involved surveying a wide range of reference materials, including books, periodicals/journals, conference papers, government publications, theses and electronic media. The main terms of reference have been 'young carers' and cognate terms such as 'care-giver'. These keywords have been used in a number of Internet academic search engines, along with other knowledge databases, such as the websites of major periodical publishing houses. Additional works have been sourced from the bibliographies of titles identified. New and often unpublished works have also been provided thanks to the generosity of other specialist researchers in this field.

An initial search via the National University of Ireland, Galway's e-Knowledge portal yielded 206 results, largely derived from the ISI Web of Science, where the terms of reference were input into the article 'subject' field, which includes title, keywords and abstract contents (see Appendix 1).<sup>1</sup> These results emanated from a wide range of international periodicals, including *Children and Society*, *Health and Social Care in the Community*, *Child Care Health and Development*, and *Child and Family Social Work*. The website of the Young Carers Research Group (see [www.lboro.ac.uk/departments/ss/centres/YCRG/](http://www.lboro.ac.uk/departments/ss/centres/YCRG/)) in the UK also proved to be an invaluable resource in relation to studies not fully represented in periodicals, as did the Social Care Institute for Excellence (see [www.scie.org.uk/](http://www.scie.org.uk/)) and the Princess Royal Trust for Carers (see [www.carers.org/](http://www.carers.org/)), also in the UK, and the American Association of Caregiving Youth (see [www.aacy.org/](http://www.aacy.org/)). Further terms of reference, such as 'informal care', were also used to search for additional literature on specific themes.

On closer inspection, however, a significant number of these publications were revealed to be outside the parameters of this review, in not actually being studies of 'young carers' but rather of related areas, such as young parents caring for their own children or young people in care systems. These studies were identified and excluded by reading the abstracts and/or the articles themselves.

The literature surveyed was broad in terms of geographical scope. In recent years, significant studies have been conducted in Malta, the Netherlands, USA and Canada, although by far the greatest preponderance of studies has been in the UK and Australia – see, for example, on the UK, Dearden and Becker (2000 and 2004), Frank *et al* (1999) and Thomas (2001); and on Australia, various reports produced by Carers Australia and Carers Victoria. Interesting studies have also emerged recently from New Zealand (Gaffney, 2007) and sub-Saharan Africa, in the latter case dealing in particularly with young carers and the HIV/AIDS pandemic (Robson *et al*, 2006).

## National and international law, policy and practice

The starting point for this review has been to examine recent literature on law, policy and practice in relation to young carers. This includes an examination of the situation in Ireland and in other national contexts.

### Situation in Ireland

There is no national legislation that specifically protects the rights and welfare of young carers in Ireland. Looking to international frameworks, Ireland is legally bound by the provisions of the UN Convention on the Rights of the Child (CRC).<sup>2</sup> Ireland ratified the CRC in 1992 and thereby made a commitment to 'respect and ensure' the rights set forth in the Convention (Article 2).

The CRC may be considered as representing best international practice regarding children's rights. The following fundamental rights protected under the CRC are relevant to young carers in Ireland and elsewhere, and particularly pertinent when one considers the potential impact of caring on children and young people:

- **Article 3** enshrines the best interests of the child principle. It provides that in all actions concerning children, whether undertaken by public or private bodies, the best interests of the child should be paramount.
- **Article 5** places an obligation on Statutory Parties to respect the responsibilities, rights and duties of parents. For example, it has been argued that a lack of support to disabled parents in their parenting role undermines this Article (Dearden and Becker, 2002).
- **Article 17** requires that a child shall have access to information and material especially those aimed at the promotion of their well-being and health.

<sup>1</sup> Conducting a search of 'any word' in the search engine yielded 866 citations; however, the majority of these references were either of no relevance to the present research, book reviews or did not relate to actual studies, e.g. review articles (see Appendix 1).

<sup>2</sup> Although legally binding, there is no judicial enforcement mechanism and currently no right of individual complaint under the CRC.

- **Article 24** recognises the right of the child to the enjoyment of the highest attainable standard of health.
- **Article 27** recognises the right to a standard of living adequate for the child's physical, mental, spiritual, moral and social development.
- **Articles 28 and 29** protect the child's right to education.
- **Article 31** protects the right of the child to rest and leisure, to engage in play and recreational activities.
- **Article 32.1** recognises 'the right ... to be protected from economic exploitation and from performing any work that is likely to be hazardous or to interfere with the child's education, or to be harmful to the child's health or physical, mental, spiritual, moral or social development'.

There is currently no national policy strategy focusing on young carers in Ireland. The National Partnership Agreement *Towards 2016* contained a commitment to develop a National Carers' Strategy and an interdepartmental working group was established in January 2008 to develop it. The strategy was to set out the Government's vision for family and informal carers and establish a set of goals and actions in areas such as income support, healthcare and services, housing, transport, information services, labour market issues, programmes of training (during caring and post-caring), social inclusion, and research and technology development. However, in March 2009 the Government announced that it had decided not to publish the strategy. The Minister for Social and Family Affairs, Mary Hanafin, TD, stated in a press release (3 March 2009) that 'the economic situation we are all facing makes it difficult to commit to major advances in services for carers'.

Carer representative groups have suggested this is a set-back for the rights of carers, including young carers, since the strategy would have represented 'formal recognition of the valuable contribution' of family carers to Irish society (Care Alliance Ireland, 2009). Ireland is not alone in this respect, however, as most other developed and developing countries lack legislation, policy and services in this area. As Becker (2007, p. 43) argues, awareness, policies and services in 'most other developed and developing countries can be classified as preliminary at best or emerging'. However, compliance with the CRC suggests the need to address this situation.

Activists for children and young people in Ireland often advocate a rights-based approach when calling for better services and supports for children, including young carers. The Children's Rights Alliance (2008), in its submission in relation to the proposed National Carers' Strategy, noted that little is known about the numbers of young carers in Ireland and argued that there is a clear link between the need for children and young people to be carers and inadequate service provision for families living with disability and illness. It was argued, for the Government to be fully compliant with the CRC, it must ensure no child is burdened with 'inappropriate care' and that 'the best interests of the child' is the primary consideration.

In 2007, the Ombudsman for Children commissioned a report entitled *Barriers to the Realisation of Children's Rights in Ireland*; it called for 'a child focus and a children's rights approach to law and policy', along with 'effective complaints procedures and advocacy' (Kilkelly, 2007, p. 170). It highlighted the problems children face in the realisation of their rights in a number of specific contexts: children in the care system and the criminal justice system; Traveller children; immigrant and asylum-seeking children; children in poverty; and children at risk of abuse and neglect. Interestingly, the report did not identify the situation of young carers as a potential barrier to the realisation of children's rights (*ibid*, p. 169). As we shall see from the research cited later, however, the impact of caring on the life of the young carer may be mediated through various social factors, including poverty, isolation and poor service provision, and the negative impacts of caring can be intensified by such social factors. What is more, caring in and of itself can result in negative consequences for the carer.

Up until now, little was known about the situation of young carers in Ireland due to a scarcity of studies focusing on their experiences. However, the studies by Halpenny and Gilligan (2004) and O'Connell *et al* (2008) deserve particular mention. The Halpenny and Gilligan report provides



a comprehensive review of the then existing national and international literature in the area of young carers, with the intention of identifying key conceptual issues. The authors provide an overview of a number of theoretical perspectives, including the medical model, the family model and the disability rights perspective. They highlight several methodological and policy issues, discussed in detail below, such as the critique of the young carers' perspective (or children's rights perspective) from the disability rights perspective, which may have an impact on the study of young carers.

At the conclusion of their study, Halpenny and Gilligan (2004, pp. 45-46) make the following recommendations for research in the area of young carers: research is required to ascertain the number of young carers, the range of tasks they perform and the length of time spent as a carer; greater insight is needed into the lived experience of young carers on a daily basis and the meaning and impact of caring roles in their lives; a comprehensive 'whole family' approach is required in the development of assessment and services; and the quality of available support, both formal and informal, must be explored. This present study has gone some way towards achieving these recommendations, in that its interviews with young carers (as well as interviews with agency staff) have generated data on the range of tasks they perform, the length of time spent caring, the lived experience of carers and the quality of available support, both formal and informal; in addition, census statistics in the future will be changed to provide estimates of the number of young carers in the Irish population.

Some years after Halpenny and Gilligan's 2004 report, O'Connell *et al* (2008) conducted the first in-depth qualitative exploratory study of young carers in Ireland, focused exclusively on the Cork region. Using a sample of 9 young carers (consisting of 5 young carers and 4 former young carers from Cork city and county), the study examined the nature of their caring responsibilities and experiences, including the impact these experiences had on their lives. The authors identified a number of negative impacts of caring on the physical and mental health of the participants and, arising from their findings, made a number of policy and institutional recommendations.

## International situation

### United Kingdom

The Young Carers Research Group (YCRG) in the UK has been the most prolific source of original research in the area of young carers, from key figures including Saul Becker and Jo Aldridge. The YCRG conducts high-quality research, evaluation and consultancy on all matters relating to children with caring responsibilities. Since 1992, there has been a steady output of books, reports and journal articles focused on themes such as young people caring for parents with mental illness (Aldridge and Becker, 2003), Parkinson's Disease, Multiple Sclerosis and HIV/AIDS.

Researchers at the YCRG, and elsewhere in the UK, have conducted numerous qualitative studies involving in-depth interviews with small samples of young carers (Aldridge 2006; Thomas *et al*, 2003; Roche and Tucker, 2003; Underdown, 2002; Butler and Astbury, 2005). The YCRG has also conducted three national surveys of young carers in 1995, 1997 and 2004, receiving support from specialist 'young carers projects'. The 2004 survey was based on data collected from a total of 6,178 carers (Dearden and Becker, 2004, p. 3).

Initial research on young carers in the UK painted a picture of 'neglect' (Aldridge and Becker, 1997, p. 1). This led to efforts from within the YCRG to establish the non-statutory 'Befriending Programme' in the late 1990s. It arose from research based on the personal accounts of young carers, which uncovered a 'common and urgently expressed need ... for "someone to talk to" – someone they could trust, who would listen and understand their lives both as children *and* as carers' (*ibid*, p. 1).

Perhaps as a reflection of the impact of the work of the YCRG, policy and accompanying legislation in the UK has now become relatively well-developed. Relevant legislation in the UK includes the

Carers (Recognition and Services) Act 1995. It provides that carers of all ages, including young carers, can request their local authority to carry out an assessment of their ability to provide care. In addition, the *Policy Guidance and Practice Guide*, which accompanies the Carers Act, provides that a young carer may be a 'child in need' as defined under the Children Act 1989 and thereby will be entitled to access services under this Act. Under the Children Act 1989, children are considered to be 'in need' if, *inter alia*, they are unlikely to achieve or maintain, or to have the opportunity to achieve or maintain, a reasonable standard of health or development without the provision of services by a local authority.

In addition, the UK Carers and Disabled Children Act 2000 provides that at the request of a carer, over the age of 16 and who provides care for someone over the age of 18, a local authority must carry out an assessment of the carer's needs even if the person receiving care has not requested to be assessed. On making its assessment, the local authority will consider whether to provide services to the carer. These services may take the form of physical help or other forms of support, vouchers to secure community care, services to enable the carer to take a short-term break and direct payments in lieu of services that otherwise would have been provided by the local authority. The combined effect of this legislative basis in the UK is that young carers have, it seems, a variety of means of accessing support and assistance via their local authorities.

However, of the 6,178 young carers participating in the 2004 UK survey, the needs of only '18% (885) had been assessed, most (11%) under the Children Act' (Dearden and Becker, 2004, p. 12). One important finding from that study concerns whose needs were assessed. The study reveals that 25% of young carers from 'black and ethnic minorities' had been assessed compared to 17% of 'white' young carers. Children caring for a relative with drug or alcohol problems were also more likely to receive an assessment and of these 68% were living in lone-parent families. Crucially, there were no statistically significant differences between white and black families in relation to hours spent caring, and the only difference between carers in two-parent and lone-parent families was that in the latter the carer was more likely to care for a parent. The other important finding concerns the reason for the assessment. It is not possible to establish whether the assessments arose because of a perceived vulnerability of the children as carers or because of child protection concerns, but the authors hypothesise that if concerns over a parent's drug or alcohol use are accompanied by mental health problems, this 'may lead to child protection procedures' (*ibid*).

If that is the case, young carers are having their needs assessed by and large when there is a child protection concern, despite the presence of the Carers Act 1995. As Roche and Tucker (2003, p. 447) point out, under the Carers Act 'the local authority are only under a duty to "have regard" to the ability of the carer to provide and continue to provide care'; and if they do undertake an assessment, they are not under a duty to provide services to the carer 'though it should influence the provision of services for the person being cared for'.

Moreover, the role young carers play, and the impact of caring, is often unnoticed or ignored by professionals (Aldridge, 2006, p. 84; Gray *et al*, 2008; Underdown, 2002) or caring is seen as a 'natural' or 'normal' preparation for motherhood for young girls (Roche and Tucker, 2003, p. 449). A briefing paper prepared by the Social Care Institute for Excellence in the UK makes the point that only a small number of young carers are currently being identified or assessed for support (SCIE, 2005). The reasons for this situation include 'blurred boundaries of responsibility between adults and children's services; a lack of awareness among many professional groups of young carers' needs and concerns; and young carers' own lack of awareness of their entitlements and their reluctance to seek formal help' (*ibid*, p. 1).

If there are doubts over the efficacy of statutory services for young carers in the UK, the non-statutory 'young carers projects' have been found to be more successful in providing services to and supporting the interests of young carers. As Butler and Astbury's (2005) evaluation of the Cornwall Young Carers Project (CYCP) found, its guiding principles were to develop and provide quality services 'in supporting young carers', to maximise 'opportunities for the social, educational and personal development of young carers' and to raise awareness and knowledge among various agencies so

as to ‘increase and facilitate partnership building’ (*ibid*, p. 293). Over a 2-year period, the project identified 202 young carers, with the vast majority (87%) of referrals coming from social services and hardly any coming from schools or general practices (*ibid*, pp. 295-96). So as to assess the needs of the young carers, consultations were held with young carers, their families and service providers. The needs identified related to social isolation, problems at school, lack of time for leisure activities and lack of recognition of their caring role. The services provided included ‘consultation, respite, transport, education and training, mentoring and support’, while young carers themselves called for more contact with project leaders and more access to other young carers (*ibid*, p. 300). Finally, a partnership-building process was essential to the working relationship required across a spectrum of agencies; central to this were various awareness-raising methods, such as presentations, information-sharing and collaborative case studies and review. The authors note that the identification of 202 new young carers shows the need for such a service and also that in coming years larger numbers are likely to be identified, although this is reliant on greater awareness-raising. Moreover, direct consultation with young carers themselves ‘has begun to address the unique needs of a previously “invisible” population’ (*ibid*, p. 302).

### Australia

Turning to Australia, a considerable body of work has been undertaken exploring the lives of young carers, most prominently by Carers Australia, Carers Victoria and researchers such as Ros Morrow and Tim Moore. While much research exists, this has not been translated into legal entitlements for young carers for assessments or service provision, as is the case in the UK (*see above*). Despite this, however, policy and services for young carers in Australia are well-developed and delivered by statutory and non-statutory organisations. For example, the Australian Government (2009) funds the Young Carer Respite and Information Services Program, which:

- assists young carers to better manage their educational and caring responsibilities;
- enables young carers to access age-appropriate support and respite services to undertake activities such as studying for exams and to attend education, training or recreation;
- provides a range of information, advice and referral services, including referral to counselling, to support young carers in managing the challenges they face as part of their caring role.

The information, advice and referral services provided by Carers Australia and its network of Carer Associations include websites for young carers with readily accessible information, support groups and young carer forums, the outcomes of which are fed into national policy.

## Informal care

The prominence of the tradition of informal care in Ireland was recognised in the original OMCYA tender, although there is little in the way of published empirical evidence documenting this practice. This is the case for informal care by both adults and young carers.

### Adult carers

The 2006 Census in Ireland identified 160,917 people as carers, representing 4.2% of the Irish population aged over 15 years (CSO, 2007). A report by Comhairle (2002) takes note of the fact that the care of older people and those with disabilities in Ireland has historically been carried out by women, who had little or no opportunity to participate in the labour market outside the home. This is confirmed in a recent report by the Carers Association (2009), which documents that the majority of carers in the country are female, accounting for 62% of all carers.

It is argued that this informal care model is becoming increasingly unsustainable, as the numbers in need of care increase and the numbers willing and able to provide largely unpaid informal care decrease (Comhairle, 2002, p. 12). While children and young people as carers are not specifically addressed in the Comhairle report, it is conceivable that they may be called on to carry out extra responsibilities in households where adults are unwilling or unable to provide the required care.

Statutory support for carers is available through the Health Service Executive (HSE), whether in the form of a Home Care Package or mainstream services. Therefore, informal care is usually in the context of formal supports, such as carer training, counselling, respite care and home care. Further statutory recognition of and financial support for informal carers is provided in Ireland using three main schemes, disbursed through the recently renamed Department of Social Protection (formerly, the Department of Social and Family Affairs):

- the Carer's Allowance is a means-tested payment and the recipient must be the full-time carer and be 18 years or older;
- the Carer's Benefit is for people who leave the workforce to care for someone; there is no specific age requirement, but the recipient must have built up sufficient PRSI contributions;
- the Respite Care Grant is given to recipients who are the full-time carers involved and are aged 16 years or older.

In addition to the supports provided by the statutory sector, a number of non-statutory carer groups have developed over the years to provide practical assistance to those who care for others, perhaps most prominently the Carers Association (*see* [www.carersireland.com](http://www.carersireland.com)).

Taking a critical view of young carers' literature, Parker and Clarke (2002) contend that informal and unpaid care, particularly that delivered within the family, plays an essential role in maintaining low levels of social care service provision. The authors refer to an 'unholy trio' of broad policy objectives: deinstitutionalisation, keeping the cost of care down and encouraging individuals and families to take on the responsibilities. They claim that all three taken together lead to the necessity of unpaid care.

### Prevalence of young carers according to recent statistical evidence

As studies of young carers tend to show, prevalence is largely unknown and this is because caring is an informal and/or hidden activity. While there is greater recognition of caring in areas such as adults looking after the elderly in an ageing population (although this is less of a problem in Ireland compared to other European societies – *see*, for example, Fahey and Field, 2008), there is less focus on caring for other needs groups.

It may also be the case that studies of young carers have been under-funded, and thus limited in geographical scope, or have had specific objectives, such as focusing on particular care experiences, which have entailed non-representative sampling approaches. Furthermore, recognition of young carers by service providers, school staff, the wider community and young carers themselves is also a problem identified by many studies (Waters and Rigby, 2008; Thomas *et al*, 2003). This makes it all the more difficult to include young carers in research and to draw a sample that captures the full range of caring experiences. Problems in identifying, and subsequently supporting, young carers are evident from many studies and this potentially compromises the validity of what statistical evidence there is on prevalence. A lack of understanding within services as to who young carers are and what it is they do may also contribute to this lack of statistical clarity.

Recent census statistics in Ireland provide some indication of possible levels of young people caring, although only for those aged 15 and older. In the 2006 Census, there were 12,286 carers between the ages of 15 and 24 from a total carer population of 160,917 (CSO, 2007, p. 134). Further analysis shows that (1) 5,433 of these 12,286 carers were aged 15-19; and (2) there was a total of 3,166 carers aged 15-17 across Ireland out of a total population in this age category of 171,585.<sup>3</sup> Of these young carers, 81% (2,561) reported providing between 1-14 hours unpaid work per week; 8% (254) provided between 15-28 hours of care per week; 4% (131) provided 29-42 hours of care per week; and 7% (220) reported providing more than 43 hours of care per week.<sup>4</sup> While

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<sup>3</sup> This additional data was provided by the CSO at the request of the Carers Association, who in turn made it available to the research team for this study.

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the vast majority of young carers perform less than 15 hours of care per week, a different picture emerges from 2006 Census data on the hours of unpaid care provided by carers of all ages. Of a total carer population of 160,917, 12,286 (8%) provided between 15-24 hours of care per week; 57,599 (36%) provided between 24-44 hours of care per week; 72,880 (45%) provided between 45-64 hours of care per week; and 18,152 (11%) provided more than 65 hours of care per week.<sup>5</sup>

Further information on young carers is provided by research findings. In addition to the study by O'Connell *et al* (2008), mentioned above, an unpublished pilot study on the needs of young carers, cited in Halpenny and Gilligan (2004), was undertaken by the Carers Association in 1997.<sup>6</sup> A sample of 15 cases illustrated different caring scenarios and impacts (e.g. on health and education), but there was little indication as to broader trends and prevalence in the Irish population.

More light is shed on those caring for family members with mental illness in a report by Kartalova-O'Doherty *et al* (2006). The authors examine the situation of carers coping with the mental illness of a family member and the issue of care-giver's distress. The 38 participants in the study also provided an approximation of the average number of hours of contact per week they had with their ill relative in the preceding 12 months: the outcome ranged from 0.1 to 100 hours per week, with an average of 39.1 hours. Parents rather than children bore the brunt of this caring load: mothers had the highest average number of hours of contact per week with the person cared for ( $n = 23$ , 60.5%, 49.1 hours), followed by fathers ( $n = 9$ , 23.7%; 30.7 hours) and sisters ( $n = 3$ , 7.9%; 24 hours), also suggesting a gender dimension to caring (*ibid*, p. 49).

Halpenny and Gilligan (2004) also refer to a number of studies in Ireland which, although not analyses of young carers per se, do focus on the experiences of children in families where there is a significant care need. One study examined the experiences of children living with a parent with schizophrenia, which involved interviews with 37 children aged 8-16; the study found that emotional distress was openly acknowledged and that this was compounded by the stigma associated with mental illness (Somers, 1997). Another study carried out interviews with 13 siblings of children with acquired brain injury (ABI) and found that the main support needed was 'practical help' (Heary *et al*, 2003). In a further study of children's experiences of parental separation in Ireland, 60 children aged 8-17 were interviewed; findings showed that children willingly undertook additional household tasks in this situation and that this was attended with both difficulties and benefits (Hogan *et al*, 2002).

In the UK, the Young Carers Research Group carried out its third national survey of young carers in 2004 (Dearden and Becker, 2004). The report is based on data collected from 87 'young carers projects', with 6,178 participants in the study. The average age of respondents was 12, 84% were white and 56% lived in lone-parent families. The majority of people with care needs were mothers, in particular in lone-parent families. In two-parent families, 46% of the people receiving care were siblings. Only 4% of adults with care needs were in employment.

Elsewhere in Europe, there is little or no quantitative work in respect to exploring caring experiences within youth populations. Most work undertaken on young carers is qualitative, albeit often using structured or semi-structured interviews which provide *de facto* quantitative indices. However, with methodologies employing sampling approaches based on referrals to agencies and/or snowballing techniques, there is little or no opportunity to gauge prevalence. Furthermore, many qualitative studies also suffered from having extremely small sample sizes. For example, the study conducted by Grant *et al* (2008) had a sample of 10 cases, while that of Bolas *et al* (2007) had only 5 cases.

<sup>5</sup> This is part of the additional data provided by the CSO and made available by the Carers Association to the research team for this study.

<sup>6</sup> For a perspective on young carers in Northern Ireland, see Tatum (1999).

A further information deficit concerns the actual ages at which children and young people become carers and the length of their caring careers. With regard to the youthfulness of young carers, a Scottish study by Banks *et al* (2002a) has shown that a high proportion of young carers in that country are aged below 12. However, there are no national statistics available in Ireland to reveal whether the situation is similar here.

## Key themes and debates in literature

The literature on young carers includes a number of important debates, focusing on certain key themes, which are explored below.

### The debate over children's rights

Given the significance in the literature of claims regarding the 'rights' of young carers, it is important to examine the concerns surrounding the children's rights approach and what is perceived by some to be a conflict between it and the disability rights approach.

There is a debate on the moral status of children and it focuses on whether, morally speaking, children can claim rights and what those rights are. Can children have all the rights that adults have? According to some, they cannot since children do not have the *capacities* needed to exercise all the rights normally granted to adults. This would seem to be the case if 'the function of rights is to protect the *choices* of the right-bearer' (Brennan, 2002, p. 55; *see also* Hart, 1973; Sumner, 1987; Steiner, 1994). Children, it is argued, lack certain cognitive and volitional capacities required for agency, and it is for this reason that children cannot have 'liberty' rights, i.e. rights protecting choices (for a discussion of this debate, *see* Archard, 2002). However, even if this is true of infants and many young children, it does not follow that adolescents also lack such capacities. What is more, some rights can be enjoyed as and when the young person develops the appropriate capacities (Archard, 2004, p. 65). This is particularly relevant for any young person who is also a 'carer'. A young carer has, by definition, developed some important capacities and taken on some important responsibilities, and it is reasonable to accept that certain agency or liberty rights should therefore be recognised as well.

According to a second, alternative rights paradigm, rights are protections of fundamental *interests* (Raz, 1984) rather than protections of choice. If children and young people have fundamental interests, then rights should protect those interests. Furthermore, one can 'have' a right even if one cannot 'claim' a right, i.e. if one does not have the agency necessary to secure one's own rights. Not all those who would normally be said to have rights are always in a position to claim them, as is the case sometimes with the elderly, people with a disability, the very ill (Brennan, 2002, p. 54) and, of course, the very young. Although this would seem to be a less contentious account of children's rights, it may be said to fail to take up the issue of just how much liberty and agency young people, including young carers, should have as a matter of right. (For a critique of a rights-based approach to children, *see* O'Neill, 1989.)

A focus on 'disability rights' provides an alternative perspective, to the extent that it highlights the needs and claims of people with a disability, whether they are adults or children. The National Disability Authority (NDA), employing a 'social' model of disability, argues that it is the social context that creates barriers for disabled people, not the disability itself (NDA, 2003). The NDA's objective is to support and assist 'independent living' for people with a disability, along with community-based and equitable services (Halpenny and Gilligan, 2004; *see also* Disability Federation of Ireland, 2003). Moreover, it has been contended, the 'disability rights' approach is in tension (if not in conflict) with the children's rights approach in so far as the latter perpetuates a view of disabled parents as 'dependent, needy and even selfish' (Olsen, 1996, p. 41). For Olsen, 'the approach has generally been one of pathologising disabled parents, of looking for parenting



deficits, and has lacked critical analysis of why disabled parents should be under the “problem” microscope at all’ (*ibid*, p. 47). Furthermore, the objective of law, policy and services, it is argued, should be to ensure independent living for people with a disability, thereby reducing, if not eliminating altogether, the need for young carers.

While both the children’s rights and the disability rights approaches may lead to conflicting claims and principles, a ‘whole family’ or ‘family support’ approach promises to resolve such conflicts. The three goals of the National Children’s Strategy are that children will have a voice, that children’s lives will be better understood and that children will receive quality support and services to promote all aspects of their development (Department of Health and Children, 2000). These goals can be attained, it is argued, only by guaranteeing children’s human rights, as set out in the UN Convention on the Rights of the Child, but this is not incompatible with support for families. Indeed, both formal and informal supports for children are necessary. Elsewhere, it has been noted that informal care by itself does not provide for the needs of people with a disability: census statistics reveal there is ‘something more than two persons with a disability for every unpaid carer’ and therefore ‘the proportion of people with disabilities receiving unpaid care is somewhere under a half’ (Fahey and Field, 2008, p. 62). It should, however, be noted that such figures are likely to underestimate the numbers of young carers (*see above*, ‘Prevalence of young carers’).

### Definitions of ‘young carers’

The issue of defining ‘young carers’ is complex and often controversial. It involves determining when a situation has developed beyond a ‘normal’ family relationship, which may involve mutual care as a matter of course. There are also situations where a child is not caring directly for a family member but is taking on additional work in the home, such as caring for siblings or undertaking household tasks to an extent beyond what would ‘normally be expected’ (Thomas *et al*, 2003, p. 36). There are therefore problems in defining ‘young carers’ related to what it is these children and young people do and the extent to which they do it.

Gray *et al* (2008, p. 169) define ‘young carers’ as:

[...] being under the age of 18 whose lives are affected by the care needs of another person, who may have any disability or long-term illness. Young carers provide, or help to provide, care and support to that person and take on a level of responsibility usually associated with an adult.

Frank (2002, p. 7) emphasizes the ‘continuum of caring’ in his definition of young carers:

There is a continuum of caring onto which all children fit somewhere. The question is at what point, in what circumstances and by whom should these children be classed as ‘young carers’? It is important to differentiate between a ‘normal’ level of ‘caring’ within a family and a level of inappropriate physical or emotional caring that affects a child’s own personal, social and educational development. Moreover, some children see themselves as young carers, while others do not. It is important to listen to their points of view about definition and perception.

A further definition by Thomas *et al* (2003, p. 44) draws attention to the service needs of young carers:

A young carer is a child or 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 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.

Building on the work of Gray *et al* (2008), Frank (2002) and Thomas *et al* (2003), the research team for this study combined the definitions to arrive at a working description of ‘young carers’ that is clear and precise and encompasses the full range of young carers’ experiences:

A young carer is a child or young person under 18 years whose life is affected in a significant way by the need to provide care for a family or household member who has an illness, disability, addiction or other care requirement. This may include a child or young person who provides direct personal care or who takes on a supportive role for the main carer. A young carer may carry out domestic tasks or may provide general, intimate or emotional care. These needs may arise on a regular or on an occasional basis. There is therefore a continuum of caring and as a result the service requirements of young carers will vary. It is important to differentiate between a level of caring that has largely positive consequences and a level of physical or emotional caring that impairs the child’s health, development or welfare.

As Thomas *et al* (2003) emphasize, a young carer need not be the primary carer and need not provide direct personal care to another household member. There are many young people whose lives are significantly affected by the ‘supportive role’ they play as a secondary carer or even by the extra ‘domestic’ duties they undertake as a result of the need for care. The working definition of ‘young carers’ should be broad enough to include the ‘continuum of caring’ identified by Frank (2002) and therefore it should include both predominant (primary) and (supportive) secondary carers, those caring for adults and children, those whose caring role leads to both minor and significant service needs, and finally it should include the various tasks performed.

Some have rejected the use of such a broad definition of young carers, arguing that it exaggerates the numbers of carers and creates a new (inaccurate and stigmatising) ‘welfare category’ (Olsen, 2000, p. 384). However, if a young person’s life is affected by the need to provide care to a family member, and also if they are as a result denied ordinary social or educational opportunities, this is a phenomenon that may deserve the attention and significance suggested by the term ‘young carer’. It has also been argued that the ascription of the term ‘young carer’ is arbitrary since it assumes there is a ‘normal’ childhood experience against which the experience of a young carer is contrasted, whereas in fact there is no uniform experience of opportunities, relationships with family members and emotional stress and anxiety (*ibid*, p. 386). However, we do not need to assume that the majority of children and young persons do conform to a norm of childhood experiences to be justified in using this definition of young carers. We need only be happy that there is a standard that should be aspired to and that the experience of being a young carer can lead to developments that deviate significantly from that standard.

### Consideration of how children and young people become carers

Thomas *et al* (2003, p. 35) observed that, in the literature on young carers, researchers have offered the following explanations for why a child or young person takes on caring responsibilities: it may be that one or both parents are ill or disabled (Frank, 1995); the absence or death of one parent can coincide with the illness or disability of the other (Aldridge and Becker, 1993); the parent who is not ill or disabled may need to go out to work (Frank, 1995); other members of the family may make themselves unavailable for caring work (Aldridge and Becker, 1993); or support from statutory agencies, the family and/or community may be inadequate (Booth and Booth, 1998). Thus, there are many reasons why children and young people become carers, with the presence of parental or sibling illness or disability often acting as the ‘trigger’ (Aldridge and Becker, 1999, p. 304). It should be added that young carers may care for anyone in the household and in some cases this will be neither a parent nor a sibling.

The onset of such conditions can mean that children and young people are gradually socialised into their role, although it must also be borne in mind that many young people actually want to care for their ill or disabled relatives (Banks *et al*, 2002a, p. 235). Dearden and Becker (1998) have also found that the likelihood of involvement in care increases with age, with girls being more involved in all aspects of care, but especially in domestic chores and intimate care. Children’s availability through co-residency with their parent(s) presents an obvious opportunity for them to be utilised



as carers in the home should the need arise (Aldridge, 2008, p. 260). Trying to prevent them from doing so may prove futile due to family loyalties and the possible hidden nature of caring from the outside world (*see below*, 'Invisibility of young carers').

It should also be noted that not all children with ill or disabled parents or other household members become young carers and that a family may receive all the practical, emotional and financial support it needs from 'a range of other sources' (SCIE, 2005, p. 3). Many young carers do, however, live in lone-parent families, with usually, though not always, a mother (Dearden and Becker, 1998). Thus, the absence of a parent means that one potential source of support within the family is gone. This perspective does not, however, take into account the fact that a parent who is present may not provide care to a spouse or child because he or she has other responsibilities or because they lack the competence or capacity or desire to do so.

### Awareness of the variability of care experiences

Young carers do not form a homogeneous group since the levels and forms of care they provide are not uniform (SCIE, 2005, p. 1). However, the diversity of caring situations is not always captured by studies of young carers because they have been largely conducted in terms of the condition of the person cared for (e.g. physical or mental illness/impairment) rather than from the perspective of young carers themselves. This is not so much a criticism of researchers and authors or their work, but rather a reflection of the particular policy orientations of thematic studies and the priorities of those funding the research. A number of other studies have also been conducted from the authors' particular theoretical viewpoints, such as the phenomenological study by Bolas *et al* (2007) or the feminist-informed work by Cass (2007). There are, however, exceptions, where issues such as support to young carers were the focus of attention, in particular Moore and McArthur's (2007) Australian study.

The diversity of studies does, however, help reflect and raise awareness of the variability of care experiences for young people. Halpenny and Gilligan (2004, p. 13) state that young carers usually provide care in the context of living with chronically ill or disabled parents, although carers can also help parents with drug or alcohol dependency problems or support other family members in need, such as siblings.

The different places of children and young people within care networks are also important to consider. Studies make clear that children and young people rarely, in fact, care alone: they more typically form part of a care network or a 'care team' (Moore and McArthur, 2007, p. 564), which may include other family members, friends and social services. Research in New Zealand by Gaffney (2007, p. 5) has found that only a small number of children were involved in giving primary care, with the majority acting as secondary carers, supported by an adult. The significance of peer support for young carers has also been examined recently in an Australian pilot programme (Waters and Rigby, 2008).

### What young carers do

According to Warren (2007, p. 140), young carers undertake a greater or disproportionate range of tasks, they do so for longer and often to the detriment of taking care of themselves. Therefore, to identify young carers, it is important to identify the thresholds below which the level of care-giving goes beyond the norm. It is also crucial to identify the range of tasks undertaken.

The list of tasks performed by young carers may include:

- domestic help;
- general care, including help with feeding, medication and mobility;
- providing psychological or emotional support;
- intimate care, involving toileting, dressing and bathing;
- childcare, i.e. looking after siblings;
- other types of care, including seeking support from service providers, translating and interpreting information, helping with paying bills, post or telephone calls.

Dearden and Becker's 2004 study of young carers in the UK reveals the tasks performed by carers, with many carers performing more than one kind of task. Of the 6,178 respondents, 68% provided 'domestic help'; 48% provided 'general help'; 82% provided 'emotional support' (observing emotions and moods, providing supervision); 18% provided 'intimate care'; and 11% provided 'child care'. The health problems of those with care needs were also recorded in the survey: 50% had problems with physical health and 29% with mental health, 17% had learning difficulties and 3% suffered from a sensory impairment. The authors also noted a sharp increase in the numbers reporting to provide emotional help (from 25% in 1995 to 82% in 2004) and a decline in the numbers reporting to provide intimate care (from 23% in 1995 to 18% in 2004).

The survey also recorded how many hours per week that young people spent in caring: 15% of participants provided 5 hours or less per week; 34% provided 6-10 hours; 17% provided 11-15 hours; 16% provided 16-20 hours; 10% provided 21-30 hours; 4% provided 31-40 hours; 2% provided 41-50 hours; and 2% provided over 50 hours. Therefore, almost half (49%) of the young carers in the 2004 UK survey were providing less than 11 hours of care work per week, while close to a further half (43%) were providing 11-30 hours per week (Dearden and Becker, 2004, p. 9).

It is possible to compare these UK 2004 findings with those from the Irish 2006 Census data for carers aged 15-17. In the former, 66% reported providing up to 15 hours of care per week and 83% provided up to 20 hours per week, while in the Irish situation 81% reported providing between 1-14 hours unpaid care work per week (*see above*, 'Prevalence of young carers').

Gender can also be an important factor shaping what young carers do. Again, in Dearden and Becker's 2004 survey (pp. 8-9), it was found that girls were more involved in all aspects of care than boys. This was true in particular with regard to domestic and intimate tasks: 65% of males and 75% of females were performing domestic tasks, and 13% of males and 22% of females were providing intimate care. However, the survey also found that gender differences tend to become apparent only as carers get older. In the 5-10 and 11-15 age categories, there is no significant difference between the tasks that girls and boys perform. However, in the 16-18 age category, girls are more likely than boys to perform domestic tasks (85% compared with 69%) and intimate care (32% compared with 17%).

This makes clear that in conceptualising the role of 'young carer', it must be considered that these children and young people may be undertaking domestic and/or more specific care activities. It is not simply a case of young people occupying one role but not the other. Aldridge and Becker (2003, p. 69) do, however, suggest that rather than taking a prescriptive 'list-based' approach to conceptualising young carers, a more nuanced approach is required. Based on evidence gathered from a sample of 40 young carers of parents with mental illness, they make the point that these carers may find it hard to demarcate and define their caring roles and responsibilities from other 'normal' aspects of their lives, mainly due to difficulties in differentiating between the impact of parental illness, the influences of a wide range of other social issues and their caring duties.

The findings of Aldridge and Becker (2003) were an important influence in developing the methodological approach for the present study. Their study suggested that many of those who fit our definition of 'young carer' will not define themselves in this way. This may also be the case for parents, as well as professionals working in the field of family and child services. This is due, in part, to the fact that many of the tasks performed by a young carer will appear to be the 'normal' tasks expected of most children. It also results from the fact that many people associate the term 'young carer' with inappropriate care and onerous responsibilities, leading to a stigmatisation of the young carers and their families.

### Further issues arising from usage of the concept 'young carers'

There are a number of important issues arising from the use of the concept 'young carers'. As discussed below under 'Invisibility of young carers', young carers may not necessarily identify themselves as such or realise that there are others like themselves, and it may also be the case

that service providers fail to acknowledge young carers or have a good understanding of them (Moore and McArthur, 2007, pp. 565-66). The media may also have unfair or biased representations of young carers, stereotyping and simplifying them as 'little angels' or victims of their parents' illnesses (Aldridge, 2008, citing Deacon, 1999).

A further related issue, already discussed, is a possible clash of competing paradigms. There may be a clash between the identities of the young carer and of the individual cared for, represented, according to Aldridge (2008, p. 254) as 'a polarity between a children's rights paradigm that is about liberalism and empowerment (giving children a voice) and the rights-based approach of the disability movement, with its emphasis on the needs and rights of disabled people as parents'.

Another issue concerns whether the young person should receive support *qua* ('as a') young carer or *qua* young person. Thomas *et al* (2003, p. 42) point out that a question frequently raised in discussions on the needs of young carers is whether or not the principal objective should be to support young carers since they are doing something important, or to abandon the whole concept since children should not be taking on such responsibilities and it is their parents who should be provided with services. However, as the authors make clear, perhaps the best way forward for young carers is for agencies to work together in cooperation towards a 'whole family' approach rather than to promote the interests and rights of one at the expense of the other, or in isolation from the other (*ibid*, p. 43).

A final issue concerns the experiences of marginal groups. Lloyd (2006) provides an overview of the debate surrounding the 'exclusive' use of the concept 'young carer' in the context of unpaid care in the UK. While interest groups, such as Carers UK, have been successful in ensuring that carers occupy a prominent position on the policy agenda, a perhaps unintended consequence has been a too rigid definition of what constitutes a 'carer'. This, it is argued, has had a detrimental impact on carers in marginal positions, such as those from ethnic minority backgrounds or young carers whose caring experiences and needs differ to those of the 'adult' or mainstream carer. In other words, certain carers can be relatively empowered at the expense of other carers, typically those less visible within social care systems, leading to systemic imbalances and service users and carers being placed in competition for resources (*ibid*, p. 955). Neither does policy necessarily take into account the diversity of carers' circumstances. In particular, the gendered division of labour within families may differ across cultures. Policy responses will, at the very least, need to be informed by an awareness of such a fact.

### 'Invisibility' of young carers

The process of researching children and young people who are providing care for a family member is complicated by a tendency on the part of the carer to avoid telling others about their situation (Banks *et al*, 2002a, p. 230). In consequence, according to Halpenny and Gilligan (2004, p. 13), many young carers' experiences 'have been, and still remain, private and to a large extent invisible to those outside the family'. Morrow (2005, p. 73) also reports the anecdotal evidence that some healthcare professionals have difficulties distinguishing between a young carer and a child who 'just does things around the house'. Aldridge and Becker (1999, pp. 312-13) note that providing care in the home is something 'most if not all children are encouraged to do'. Warren (2007, p. 136) too observes that some degree of caring and household responsibility is generally looked upon as a reciprocal part of family life and a 'beneficial training ground for good citizenship'. It is therefore not surprising if professionals remain unaware of the presence of young carers, even where there is direct contact with the families in question.

This 'invisibility' issue was addressed directly by Thomas *et al* (2003) in their study exploring the 'unmet need' among young carers in Wales as a result of their 'invisibility'. It encompassed not only the reluctance of young carers to identify themselves as such, but also a lack of awareness among the professionals who might have been best placed to identify them (*ibid*, p. 39). In trying to identify young carers as participants in their study, Thomas *et al* made contact with service providers, but in doing so relied exclusively on written requests for referrals. This approach generated no referrals at all for their study.

Other empirically informed studies also make clear that much caring can be ‘covert’ (Banks *et al*, 2002a) or ‘hidden’ (O’Connell *et al*, 2008; Gray *et al*, 2008) and may not be represented in official statistics. The reasons for this lack of visibility include concerns over invasion of privacy; a fear that families will be broken-up (Banks *et al*, 2002a, p. 232; Roche and Tucker, 2003, pp. 449-50; Thomas *et al*, 2003, p. 36); wanting to avoid stigma; and fear of bullying at school (Aldridge and Becker, 2003, pp. 80-82). In a UK study carried out by the Princess Royal Trust for Carers (1999), 71% of the young carers who took part reported that they had been bullied at school and, as a direct result, 20% had not attended school. Until a way is found of enabling children and young people to feel comfortable talking about their caring roles, services provided to support young carers may only touch the tip of the iceberg (Banks *et al*, 2002a, p. 230).

### The potential impact of caring on carers

The potential *negative* impacts of caring on children and young people are well documented, including school absences and educational under-performance (O’Connell *et al*, 2008); restricted access to social networks (Marsden, 1995); health, psychological and emotional problems; physical injury; and long-term or developmental impacts (Dearden and Becker, 2000).

Grant *et al* (2008) conducted face-to-face interviews and follow-up interviews after 6 months in 11 case study sites, with up to 10 family carers per site. Bullying at school, rejection by peer groups and lack of understanding of their caring roles by teaching staff were described as ‘fairly typical’ *educational impacts* (*ibid*, p. 276). According to Morrow’s research (2005) in Western Australia, the results of which are based on questionnaires filled out by 48 young carers, the most consistent finding from parents about the impact of caring on their children was the lack of participation in after-school activities; reasons given included financial and time constraints, and having to be at home to fulfil caring responsibilities. Meanwhile, commenting on Marsden’s 1995 study of the impact of caring on education in the London Borough of Enfield, Halpenny and Gilligan (2004) note that difficulties encountered related to punctuality, attendance and delivery of homework and coursework. The study by O’Connell *et al* (2008) on young carers in Cork found that the educational impacts resulting from being a young carer ranged from missing school to difficulties balancing homework and caring responsibilities; most of the young carers interviewed received little or no support from their schools due to a lack of understanding or awareness of the situation at home. Dearden and Becker’s 2004 survey of 6,178 young carers in the UK found that a large minority (22% of those aged 5-15) were missing school or experiencing educational difficulties.

The comparative research conducted by Warren (2007, p. 142) with samples of carers and non-carers in the UK also found that the latter were ‘more likely than young carers to undertake mainstream hobbies and interests, to participate in sporting activities or to join community or specialist interest groups, such as a youth club, a music group, the Brownies or Guides’. Thus, the *social impact* of caring can certainly be considerable on a young person’s life. Similarly, O’Connell *et al* (2008) identified negative impacts on the social lives and relationships of most of the 9 young carers they interviewed in the Cork study. Impacts included having less time to spend with friends, to develop relationships and engage in social activities. Not only can the time spent providing care and the weight of caring responsibility have a detrimental impact on peer relationships, but also, according to Dearden and Becker (2000), the child or young person may also be ‘socialised’ into the role of carer, which can in itself lead to further social exclusion.

Thomas *et al* (2003, p. 40) interviewed 21 young carers aged 9-18, 8 of whom were boys. Regarding the *emotional impact* of caring, most of the children and young people who responded reported feelings of sadness or even depression. The potential negative *health impacts* of providing care are important to consider as well. Young carers risk poor health as a result of ‘a lack of self-care, sleep deprivation and anxiety’, along with ‘feelings of sadness, guilt, anger, fear and worry’ (Waters and Rigby, 2008, p. 7). There is also potentially a *physical impact* of caring. The danger of injury and physical impairment induced by tasks such as heavy lifting (Hill, 1999) has been noted, with the possibility of young people being required to perform tasks that are age-inappropriate or

developmentally inappropriate. It is also the case that children may not have been trained in how to lift a heavy load safely for the very reason that this task is hidden or covert.

Given the absence of longitudinal studies, the *long-term or developmental impact* of caring is difficult to assess. The briefing paper by the SCIE (2005), *The Health and Well-being of Young Carers*, makes the point that research findings on this issue are somewhat equivocal. Being a young carer can impact on the transition to adulthood, as it can adversely affect further or higher educational and employment opportunities. There is, however, no evidence of long-term emotional or mental health problems as a result of caring. The SCIE research also makes the point that caring does not necessarily lead to negative outcomes for children and young people (*ibid*, p. 9): 'Young carers and their parents report both positive and negative elements to providing care. Many young carers report that caring gives them feelings of maturity, and a sense of closeness to both parents and family; they also value their responsibilities and consider them to be a source of practical life skills.'

The idea of caring as an entirely negative experience is being challenged – caring may actually enhance *resilience* as opposed to creating vulnerability (Becker, 2007, p. 40; Packenham *et al*, 2007, p. 90). It is increasingly recognised that despite facing various forms of adversity, many children and young people manage to be resilient – but not invulnerable – and have successful and fulfilling lives (Canavan, 2008, pp. 1-2; Stein, 2008, p. 36). Masten (2001, p. 234) associates resilience with having connections to competent and caring adults in the family; family and community belonging; cognitive and self-regulation skills; positive self-image; and the motivation to be effective in the environment. The existence of these various relationships may therefore help mediate the emotional burden of caring.

Qualitative research was carried out by Aldridge (2006) with 40 parents diagnosed with a severe and enduring mental health problem, their children who were providing care and the professionals involved in service provision. Some positive outcomes were reported. The 'importance of interdependency' was underlined and that caring can help to 'reinforce the bonds between children and parents' (*ibid*, p. 83). This perspective offers a challenge to much prior work which, as Olsen (1996, p. 44) notes, has portrayed young carers in 'almost wholly negative terms'. Morrow's (2005) Australian study found that parents and young carers want to spend time together and feel a need to connect with one another (*ibid*, p. 74); one respondent went so far as to state that 'disability has been a blessing to our family' (*ibid*, p. 18). Newman (2002) also remarks that where problems do arise for young carers, they may be more the result of other factors, most notably poverty, social exclusion and unsupported or inadequate parenting, rather than being directly related to illness or impairment within the family (*see below*, 'Relationship between caring, health and poverty').

## Age-inappropriate care

What constitutes 'age-inappropriate care' is often difficult to translate into quantitative and qualitative indicators. However, out of all the caring tasks undertaken by children and young people, it is the provision of personal and intimate care that 'most clearly distinguishes young carers from other children and young people' (Warren, 2007, p. 140). The developmental impact of care is also particularly important to consider, with giving care at a young age frequently portrayed as a negative influence (Olsen, 1996, p. 44; Gaffney 2007, p. 8). It might be seen as a parental role reversal/exchange situation (Earley and Cushway, 2002, p. 165) or 'parentification' (*ibid*, p. 38) or 'extreme over-functioning' (Halpenny and Gilligan, 2004, p. 26), with an accompanying assumption that the cared-for are dependent and selfish (Olsen, 1996, p. 47). Hence, developmental assessments of the impact of caring need to be well-informed and balanced.

Parentification is defined as 'when a child takes on roles and responsibilities traditionally reserved for adults' (Hooper, 2007, p. 217). It involves a functional and/or emotional role reversal between child and parent, and the child sacrificing his or her own needs for attention, comfort and guidance. Ongoing periods of parentification have been found to be destructive, in particular disrupting the child's 'future functioning and ability to form adult attachment relationships'.



However, while there are linkages between child and adult attachment styles, it is also important to note that those who experience poor parenting 'are not fated to follow this interaction style forever' (*ibid*, p. 220). Moreover, the lack of longitudinal studies on young carers also entails an absence of data on whether caring by young people does lead to parentification.

Other studies have tried to establish what impacts intimate care has on the young carer. These may include social exclusion, particularly in rural areas (Butler and Astbury, 2005, p. 297); educational problems, such as missing school or exams (Roche and Tucker, 2003) and bullying (Evans *et al*, 2001, p. 70); missing out on social and leisure activities (Warren 2007, p. 142); emotional and psychological distress due to involvement in 'developmentally inappropriate' activities (Altschuler, 1997); and physical impairment induced by tasks such as heavy lifting (Hill, 1999). The Irish Children's Rights Alliance (2008, p. 4) has argued that children 'are forced to undertake inappropriate care roles when statutory healthcare services are inadequate'.

### The relationship between caring, health and poverty

There is no doubt that while caring for a relative does not automatically bring with it detrimental consequences, the risk of a broad range of negative outcomes emerging is heightened. These risks include, according to Aldridge (2008, p. 260), the potential to 'threaten or undermine children's safety and physical health and well-being ... suffer physical injuries as a result of lifting a disabled parent, for example ... [and] economic stability and well-being can be compromised'. What is more, Dearden and Becker (1997, p. 20) suggest that poor parental health is associated with a 'complex web of social disadvantage because of ... poverty and deprivation'. Financial hardship may be a consequence of a parent being unable to work, exacerbated by additional costs incurred, such as having to keep the home heated for long periods or pay for public or private transport to respite services. Moreover, the study by O'Connell *et al* (2008) concluded that financial hardship is just one aspect of the poverty implications for young carers. Reduced life chances due to the impact of caring on their education can lead to the further impoverishment of young carers in later years. The strain of having a disabled family member has also been linked to family breakup, which itself may have a negative impact on financial circumstances (Carers Victoria, 2007, p. 33).

It may not necessarily be the case that caring *per se* puts a child or young person into harm's way. But other negative factors, such as poverty or economic instability – which could in themselves have been instrumental in negating the cared-for person's capacity for looking after themselves – combine with the weight of caring to impact detrimentally on a child or young person's life. Specific negative factors may include the absence of one or more parents in the household, low income, lack of social support and deficits in social capital, e.g. missing informal support from family, friends or neighbours. Research in the USA suggests that young carers tend to live in single parent households and where household incomes are low (Sisowski, 2006). In Ireland, it should be borne in mind that many young carers live in remote and/or rural areas, often with poor transport links to family, friends and services, including medical facilities, adding to their social isolation. Rising levels of poverty due to the present economic slowdown are also a concern, leading more people to live at risk of poverty and isolation (St. Vincent de Paul, 2008).

Grant *et al* (2008) note that young carers tend to have a low self-opinion. This may be because they blame themselves for the condition of the person they are caring for, or 'adult' social services may perhaps unwittingly have reinforced a sense of negativity around them. It may also be the case that they feel they are 'underperforming' in other areas of life compared to their peers. As a means of improving young carers' sense of trust, the research points to the importance of establishing effective communications – 'honest interpersonal dialogue' (*ibid*, p. 277) – with project workers.

Conversely, work emanating from the UK's Young Carers Research Group (YCRG) has found a more positive relationship existing between caring and well-being. Children and young people may be gaining a sense of being needed and achieving something positive in their lives through caring (Aldridge and Becker, 2003; Becker *et al*, 1998). Such feelings do tend to dissipate, however, when caring becomes prolonged, disproportionate and unsupported (Aldridge and Becker, 1993 and 1994a) or positive contributions go without recognition (Aldridge and Wates, 2005).

## Learning from the literature review of 'young carers' research

This review of national and international literature on young carers suggests some central learning points for research in this area. Of particular significance are findings on 'what works' in supporting young carers, the invisibility of young carers and the methodological implications this has, and finally the existence of a continuum of caring. Key points are:

- In Ireland, there is an absence of legislation, policy and services for young carers. Ireland is not alone in this regard, but nonetheless commitments under the UN Convention on the Rights of the Child would seem to require a concerted response to the needs of young carers.
- Even in the UK, however, where legislation for young carers is in place, statutory services have not been wholly effective. The majority of young carers there do not have their needs assessed, as provided for by legislation, and the minority who are assessed are assessed under the Children Act 1989, as opposed to the Carers Act 1995. This may be due to the prioritisation of child protection issues and it may also reflect the continuing 'invisibility' of young carers due to a lack of awareness among service providers, parents and young carers themselves.
- The system of nationwide 'young carers projects' in the UK is an example of a non-statutory service response. Their goals include identifying and accessing young carers, identifying their needs, providing services to them and building partnerships across a spectrum of agencies through various awareness-raising strategies.
- The invisibility of young carers has important methodological implications. While attempts in the UK to recruit research participants from among those already belonging to 'young carers projects' have proved successful, in contrast, efforts to recruit young carers either directly through information campaigns or indirectly through written requests to agency staff have not been successful. The literature review supports the view that young carers are a 'hard to reach' population.
- Many of the studies have found that there is a continuum of caring among young people and this has important implications for efforts to recruit young carers. It may be difficult to recruit vulnerable young carers if the issue is too sensitive for parents. Equally, those young carers at the other end of the spectrum, in terms of the supports they receive and the responsibilities they take on, may also be difficult to recruit if parents, service providers and young carers themselves perceive this to be a 'normal' childhood situation. Furthermore, interview questions for young carers should be designed to capture the complexity and variety of caring situations suggested by the literature.

## Summary

- There is no national legislation that specifically protects the rights and welfare of young carers in Ireland.
- The children's rights perspective supports both the recognition of children's rights and the enforcement of legally guaranteed human rights. Under international law, Ireland is bound by the provisions of the UN Convention on the Rights of the Child (CRC). A number of fundamental rights protected under the CRC are relevant to young carers, in particular the rights to leisure, to education and to freedom from exploitative or dangerous work, as well as the principle of the best interests of the child.
- There is currently no national policy strategy focusing on young carers in Ireland. The decision in March 2009 not to develop the National Carers' Strategy is seen by non-statutory carers' organisations as a setback for the recognition and rights of young carers.
- Much can be learnt from practitioners in the UK and Australia in assessing the state of the art on international policy, practice and law on young carers.

- The rights of young carers can be justified either as protections of their liberty or as protections of their fundamental interests.
- While young carers should be supported and protected by a framework of rights, a 'whole family' approach seeks to both guarantee children's rights and to support families, thereby overcoming tensions with a disability rights approach.
- Definitions of 'young carers' need to take into account the continuum of caring and the fact that some are primary carers and others are secondary carers.
- Young people become carers for a variety of reasons. While an illness or disability in the family may act as the 'trigger', poverty, poor service provision, the unavailability of other individuals to care and other negative circumstances related to poverty are also important.
- Care experiences vary markedly among children and young people, depending on family circumstances, the condition of the person cared for and the young person's place within a care network. In the literature, it is thought that few children or young people undertake primary care responsibilities.
- According to a number of studies, the prevalence of young carers is not well-established due to possible under-recording and the hidden nature of young carers. Recent census statistics in Ireland (2006) provide some indication of possible levels of young people caring, suggesting that there are 3,166 young carers in the 15-17 age category.
- The tasks young carers undertake range from everyday domestic activities (e.g. cooking, cleaning and shopping) and child-minding, to more specific care activities, such as administering medication, helping with dressing, toileting and washing, and aiding mobility.
- Young carers themselves, their parents and service providers may not necessarily like or even accept the label 'young carers'. The term 'young carers' can be associated with inappropriate care and onerous responsibilities, leading to a stigmatisation of the young carer and family.
- The hidden or covert nature of care has important implications for researching how best to support young carers.
- The impact of care is largely discussed in studies using negative terms with regard to educational, emotional, social, physical and long-term impacts. However, young carers may also be resilient and caring may result in stronger interpersonal relationships between the carer and the person cared for.
- While it is likely that only a small number of young carers are involved in providing age-inappropriate care, these children and young people may be highly uncomfortable with providing such care, which may also have a detrimental developmental impact on them.
- Children and young people are more likely to be giving care in economically disadvantaged families.
- The negative impacts of care are more likely to be intensified by socio-economic disadvantage.



# **3** **METHODOLOGY FOR CONSULTATIONS**

As discussed in Chapter 1, the present study had 5 objectives:

1. To provide a comprehensive review of the national and international literature on children as carers, including definitions, legislation, policy and service provision.
2. To collate information about potential mechanisms that have been or currently are, or could be, used to identify young carers.
3. To examine the extent to which these mechanisms are effective in identifying young carers.
4. To recruit a sample of young carers and undertake empirical work with them on:
  - ways in which other young carers might be identified by the statutory and non-statutory sectors;
  - the extent to which caring impacts on their lives;
  - ways in which young carers could be assisted.
5. To make recommendations for the development of services for young people in situations of caring.

To meet these objectives, the research team undertook empirical work with 26 young carers and 30 agency staff. For the purpose of this study, the latter refers to service providers and representative organisations in both the statutory and non-statutory sectors, likely to have some involvement with or interest in young carers (*see Appendix 5 for an illustration of the agency sample*).

The purpose of this chapter is twofold: first, to outline the methodological choices, challenges and solutions in recruiting a sample of young carers and agency staff and undertaking empirical work with them; and, second, to document findings relating to potential recruitment mechanisms to identify young carers.

## Sampling and recruitment of young carers

### Issues pertaining to participation in the research

As detailed in the literature review (*see Chapter 2*), many studies have noted the ‘invisibility’ of young carers. The role, and the young carers themselves, are often ‘hidden’. This is the case because the children and young people, their parents and/or professionals working with the family often either do not perceive the young people to be carers as such or else do not want to bring attention to what is a sensitive situation.

Families may not use the term ‘young carer’ because of a perceived social stigma surrounding caring itself or the illness and disability in question, or because of a fear that social services will intervene in a family where young people are thought to be taking on age-inappropriate responsibilities. Alternatively, it may be thought that caring is a ‘normal’ part of a young person’s life within the family and that therefore it does not merit the significance associated with the label ‘young carer’. Further, young carers are, for the most part, not on the databases of statutory carer professionals organised by the Health Service Executive (HSE) or on those of the non-statutory carers’ organisations. Given that young carers, therefore, tend to be ‘invisible’, a crucial research question at the outset of this study was how to recruit a sample of young carers in order to undertake empirical work with them.

### Definition of ‘young carer’ for the purpose of this study

It was considered important to have a working definition of ‘young carers’ so as to ensure that data were only collected from participants relevant to the objectives of the study. Thus, the research team proceeded with the following working definition, which combines the work of Frank (2002), Gray *et al* (2008) and Thomas *et al* (2003) (*see Chapter 2 for further detail*):

A young carer is a child or young person under 18 years whose life is affected in a significant way by the need to provide care for a family or household member who has an illness, disability, addiction or other care requirement. This may include a child or young person who provides direct personal care or who takes on a supportive role for the main carer. A young carer may carry out domestic tasks or may provide general, intimate or emotional care. These needs may arise on a regular or on an occasional basis. There is therefore a continuum of caring and as a result the service requirements of young carers will vary. It is important to differentiate between a level of caring that has largely positive consequences and a level of physical or emotional caring that impairs the child's health, development or welfare.

The working definition determined who could and could not be included in the study. Those who *could* be included in the study were: primary carers; those who aid the primary carer in the provision of care; and those who perform roles or tasks as a consequence of the need for care of another family member in the home. One young carer aged 18 was considered eligible for inclusion in so far as he could comment on his experiences as a young carer in the very recent past. Two young people caring for their grandparent were included as well, and had the opportunity presented itself, the research team would have included those caring for a more distant relative in the household (e.g. a cousin or aunt or uncle) or for a non-relative living in the same household.

Those whose experiences were *not* relevant to the objectives of the study were: teenage parents caring for their own children; children and young people who provide help to parents when there is not a 'care' need in the family (e.g. children of migrant parents helping with translation); and adult carers.

## Sampling approach

The objective was to conduct interviews with 30 young carers. The aim was to access a sample of young carers in the Irish population reflective of a range of caring scenarios and a range of ages between 5-17 years. There was no 'sampling frame'<sup>7</sup> from which to draw a random sample of young carers in the Irish population. As noted earlier, young carers are, for the most part, not on the databases of HSE carer professionals or those of the non-statutory carers' organisations. In the absence of a sampling frame, the research team employed three closely related sampling methods: *purposive*, *convenience* and *snowballing* (see below).

### Purposive sample

Initially, the research team employed a purposive sampling approach. The objective of purposive sampling is 'to sample cases/participants in a strategic way, so that those sampled are relevant to the research questions that are being posed' (Bryman, 2008, p. 415). The research team drew up a list of organisations that were thought likely to have contact with, and could potentially introduce the study to, young carers. Given that a primary purpose of the study was to examine mechanisms through which young carers can be identified, it followed that the initial approaches to statutory and non-statutory agencies were at times exploratory since the research team was not yet certain which agencies, divisions or personnel would, in fact, be best suited to act as 'gatekeepers' for young carers. In social science qualitative research, it is not unusual to make use of a gatekeeper, i.e. someone who helps researchers gain access to the study population. In the statutory sector, the research team focused on HSE personnel and approached various divisions within the HSE where it would be expected to find staff who had contacts with young carers. In the non-statutory sector, the research team approached health and disability organisations and organisations with a more general remit covering children and young people.

<sup>7</sup> A sampling frame is a list of all units of the population from which a sample can be selected (Bryman, 2008, p. 168).

Other studies of an ‘invisible population’ have adopted a purposive sampling strategy. Hogan and O’Reilly (2007), for example, observe that their study of children’s experiences of domestic violence in Ireland involved ‘negotiating two stages of gatekeepers’, namely, the agency staff providing services to the parent and child, and the parents of the children. This was a time-consuming process and increased the likelihood that consent would be refused. However, it was unavoidable for ethical reasons and also because no other method of accessing the population was available.

### **Convenience sample**

The purposive sampling approach alone did not yield the desired number of participants (*see below*, ‘Recruitment of young carers’). As a result, the research team progressed to convenience sampling and snowballing sampling in addition to the purposive approach. A convenience sample is ‘one that is simply available to the researcher by virtue of its accessibility’ (Bryman, 2008, p. 183). The research team used its existing contacts in the HSE and non-governmental organisations, both service providers and representative organisations. The team approached those who had collaborated in the past on research, and could be reasonably expected to have contact with young carers, and requested their assistance in referring potential participants.

### **Snowballing**

A snowballing sample is often used when no sampling frame exists or can be created and there are difficulties in terms of cost and time in identifying and contacting participants. The method works by asking the initial group of contacts or participants to recruit others they know are in the target group (Bowling, 2002, p. 188). There is a danger (as is the case with convenience sampling) that such an approach will introduce bias since the contacts made will be heavily influenced by the initial contacts and the suggestions they generated. To address the potential for bias, the research team consciously looked for balance. In making further contacts, considerations included geographical spread and diversity in the categories of departments and agencies contacted. However, this method was appropriate to the study as the identification of young carers was a time-consuming and difficult process due to their ‘invisibility’. Further, it often happened that the initial points of contact in an organisation, whether or not they themselves could generate referrals, would make recommendations concerning who else should be contacted and the research team was aware that this information could not have been generated by any other means. Once again, this spoke directly to the objectives of the study, shedding light on mechanisms for the identification of young carers.

### **Recruitment of young carers**

Due to ethical considerations, there was to be no direct contact between the researchers and the potential participants until the young carers and their parents or guardians had expressed a willingness to participate in the study. Their willingness to participate was to be communicated to the research team via agency staff. Alternatively, potential participants were given the option of contacting the research team directly by e-mail, telephone or text following the distribution of posters and flyers, requesting them to be in contact for further information (*see Appendix 4*).

When young carers and their parents or guardians expressed a willingness to participate, information sheets and consent forms for both parents/guardians and young carers were sent by the agency in contact with the family or by the designated member of the research team (*see Appendix 8*). These were to be signed and returned to the Child and Family Research Centre at NUI Galway. After signed consent forms had been received from both parties, direct contact was made with the respondents by telephone to arrange an interview appointment.

There were two different phases of recruitment in this study, although some of the means employed in the first phase continued to be used after the start of the second phase.

### Recruitment Phase 1: October 2008 – March 2009

The first phase of recruitment involved the following two-fold strategy:

- **Seeking referrals via agencies:** An extensive list of agencies across Ireland, both statutory and non-statutory, likely to be in contact with young carers was compiled (see *Appendix 2*). This included specific services dedicated to meeting the needs of carers in the Irish population, organisations that were youth-specific in their remits, and organisations working with families with specific needs, such as disability and substance abuse. A letter was prepared, providing details of the research project, and sent to the managers or Chief Executive Officers (CEOs) of the various agencies targeted. This initial contact was followed up with telephone calls approximately one week later.

From this further contact, it immediately emerged that the majority of these agencies, while broadly supportive of the aims and objectives of the research, were not in a position to assist with the research and provide referrals due to the fact that they have no direct contact with or knowledge of young carers. While the majority of this follow-up procedure was conducted via telephone, in some cases written apologies were also received from agencies, either by post or e-mail, expressing regret that they were unable to be of assistance to the research team.

An initial relationship was established with the agencies that responded positively, in particular with the three most prominent non-statutory carers' agencies in Ireland – Carers Association, Caring for Carers and Care Alliance – in the hope of utilising their contacts to provide referrals to the study. However, this initial contact was for the most part disappointing as a method to identify and recruit young carers: agency staff were willing to help with both publicising the research and providing insight into possible issues that may arise in the lives of young carers, but there were few actual referrals made from this phase ( $n = 5$ ).

- **Seeking referrals via a nationwide information campaign:** The second strand of recruitment in this first phase was a nationwide information campaign. The research team distributed posters and flyers to all post-primary schools (760) across Ireland and to a wide range of youth organisations, including youth information centres, youth cafés and family resource centres (see *Appendix 4*). The posters and flyers requested young carers interested in taking part in the study to contact the research team for further information by e-mail, telephone or text message.

The response to this approach was again disappointing, generating only one referral. This referral was as a result of a staff member in a family resource centre seeing a poster and bringing the study to the attention of a family with a young carer and requesting their participation. Only one young person initiated contact as a result of the information campaign, requesting further information by text; however, on receiving further information, the young person did not agree to participate. Therefore, the first phase of the recruitment process generated just 6 referrals in total.

### Recruitment Phase 2: April 2009 – July 2009

By the end of March 2009, only 2 consent forms had been returned and interviews with young carers had yet to begin. The research team was aware that the original strategy to recruit young carers (although 4 further referrals would come over the next month as a result of the earlier recruitment strategies) was not, and would not by itself be, sufficient. Therefore, a radical review of the sampling and recruitment strategy was embarked upon, finally settling on the following two-stranded approach:

- **Expanding the original recruitment policy:** Since the original recruitment process did lead to some success, the research team decided to expand its contacts with agencies, both statutory and non-statutory, in an effort to generate some of the referrals that were still required. As a new strategy, the research team expanded the original purposive

sample, also employing convenience and snowballing methods. Most of those on the original list of contacts in the purposive sample were returned to again and, in addition, other contacts convenient to the research team were approached. On many occasions, these initial contacts led to other contacts and the sample snowballed (*see Appendix 3 for the additional agencies contacted during Recruitment Phase 2*).

The research team engaged by telephone personally with all agency staff contacted, establishing good relationships with a broader range of key contacts. The research team took the time to explain the concept of young carers and the nature and purpose of the research to this wider range of agency staff. In addition, a conscious effort was made to target front-line staff in both the statutory and non-statutory sectors. In most cases, the front-line staff contacted were not providing a service to the young carer, but rather providing a service to the family member in need of care. In many instances, the agency worker would agree to act as a gatekeeper for young carers and their families, and some of those families and young carers agreed to take part in the research.

- **Direct media campaign:** The research team also embarked on a direct media campaign, liaising through the Press and Information Office at NUI Galway. Press releases were sent out to national and regional print media and air-time was secured on national and regional radio news programmes to raise awareness of the study and recruit participants.

This second phase of recruitment was a vast improvement on the first, with a sample size of 20 being reached, all generated through contact with agency staff. However, it is also the case that despite exhausting all avenues the original objective to conduct interviews with 30 young carers was not achieved. The most important finding from this phase of recruitment was that the research team's personal relationships with the agency staff, acting as gatekeepers, was the single most influential factor explaining the attainment of referrals.

### *Final sample*

The final sample size was 26 young carers: 6 young carers were referred to the study by agency staff from the statutory sector, while 20 referrals came from the non-statutory sector. In the final sample, there were 7 males and 19 females, among which 10 were aged 5-11 and 16 were aged 12-18. All the participants were caring for another family member. The majority of young carers (15) were caring exclusively for a sibling(s), although a number (7) were caring exclusively for a parent(s). In addition, 2 young carers, living within the same household, were providing care to both their siblings and their father, while another 2 young carers, again living within the same household, were helping to provide care to a grandparent. The people in need of care had a range of conditions, including physical and intellectual disabilities, illnesses, including mental illness, and in one situation a sensory impairment. For full details, see 'Sample profile' in Chapter 4.

## **Sampling and recruitment of agency staff**

So far the discussion has focused on the methods used to sample and recruit young carers. However, to meet the objectives of the study, the research team also sought to undertake empirical work with 30 agency staff, both in the statutory and non-statutory sectors. The same three sampling methods (purposive, convenience and snowballing) were employed in the recruitment of agency staff. Indeed, there was considerable overlap between the two processes. Many of the agency workers recruited to take part in interviews also played a role in the recruitment of young carers and the same rationales applied to both processes.

First, the research team approached organisations thought to be germane to the purposes of the study. Many of these had played a role in the early agency liaison process and the recruitment of young carers. However, the sample was also broadened to ensure that it did not exclude important stakeholders. The research team also progressed on the basis of what was convenient in light of the contacts already made, and finally the sample snowballed on the basis of advice and suggestions from earlier contacts.

A sample was created comprising service providers and representative organisations, both statutory and non-statutory, likely to have some involvement with, or interest in, young carers (*see Appendix 5*). The sample included personnel from two key divisions in the HSE: Primary Continuing and Community Care and Population Health. The HSE personnel included those working in planning and policy, personnel in carers' services and personnel in other services such as disability, public health nursing, child care, special needs, family welfare conference coordination and social work. The research team ensured a mixture of managers, policy and front-line staff, and a regional spread. In the non-statutory sector, the participants were drawn from five key areas: physical disability organisations; carers' organisations; intellectual disability organisations; mental health organisations; and children and youth organisations. As with the HSE sample, there was a mixture of front-line, managerial and policy staff, and participants were sourced from across the country. A final category, 'Other', included those who did not fit into the above typology, but had valuable insights into the experiences of young carers.

## Interviews

### Young carer interviews

Young carers took part in informal, but in-depth interviews with the research team. Semi-structured interviews allowed the interviewees to express themselves freely in response to questions, while at the same time providing sufficient structure for ease of analysis. This enabled the production of rich and thick descriptions of the lived experiences of young carers. The collection of qualitative data was necessary in order for the research questions set to be answered: to explore the mechanisms that are being used, and could be used, to identify young carers; and also to record young carers' perspectives on the impacts of care and the supports being provided and needed.

### Instrument development and preparation

Interview schedules were designed for the age groups 5-11 and 12-17 (*see Appendix 6A and 6B*). Developing the schedules involved the use of age-appropriate language. For 5-11 year-old respondents, text was combined with symbols and illustrations to aid clarity. The literature review considerably informed the drafting of the interview schedules. Moreover, the schedules were created in consultation with agency staff, most notably HSE contacts and those attending a young carers' roundtable hosted by the Disability Federation of Ireland in December 2008. The roundtable was attended by a broad spectrum of agencies, including Carers Alliance, MS Ireland, Children's Rights Alliance, Headstrong and Aware.

The following pertinent themes were discussed at the roundtable:

- **Range of caring scenarios:** Agency staff were keen to stress the diverse nature of caring in Ireland, including families with a degenerative illness, an alcoholic parent, a parent with mental health problems and also the situation of young people 'caring for themselves'.
- **Stigma and isolation:** There may be a stigma attached to young carers and a risk of exacerbating this stigma through insensitive research questions. This may also lead to difficulties recruiting participants to studies, the lack of young carers presenting to agencies, the isolation of young carers and the negative impacts in education, social life and emotional well-being.
- **Family breakdown:** Stories about young carers frequently only emerge in the aftermath of a family breakdown. This breakdown may in itself have been the outcome of, or contributed to, difficult family circumstances.
- **Support:** Young people may be required to perform extra caring roles if and when there is insufficient service provision for the family member in need of care. Nonetheless, even when services are adequate and the family is not socially disadvantaged, the young person's life will be impacted by the care needs of a fellow-family member.
- **Flexibility:** The agencies advised that the interview schedules be used with a large degree of flexibility, given that young carers are not a homogeneous group. Education levels and even basic literacy may also vary, not to mention attention spans. It was advised



that consideration should also be given to the specific circumstances of the children and young people themselves. Therefore, a relatively unstructured approach was followed when conducting interviews. Moreover, so as to better capture the complexity of the caring situation, this study asked respondents a variety of questions concerning their home life.

Given the difficulties in identifying and recruiting young carers, the research team considered that a separate pilot study to test the design of the interview schedules was not feasible. As an alternative, interviews with the first young carer participants from the different age groups (those aged 5-11 and 12-17) were treated as *de facto* pilots. Following these first interviews, it became evident that the images that served as prompts in the interview schedule for 5-11 year-olds were primarily geared towards a young person caring for an adult. Consequently, the interview schedule was revised to incorporate more illustrations representing caring for siblings. It also became evident at this stage that many of the 9-11 year-olds were very competent and articulate. Therefore, the researcher conducting the interviews would use a combination of the interview schedule for those aged 5-11 and 12-17 for this age group when considered appropriate.

### Interview process

The research team was aware of the need to minimise disruption to respondents. The location for the interview was of the respondent's choosing and the time of interview at their convenience. All the interviews, apart from two, took place in the home at the respondent's request.<sup>8</sup> The interview itself lasted no more than an hour and respondents were free to end the interview at any time. For respondents aged 5-11, another adult (either a parent or a guardian) was present at all times during the interview. For respondents aged 12-17, a parent or guardian was in close proximity.

The interviews were semi-structured and covered a number of areas (*see Appendix 6A and 6B*):

- demographic data was collected from all participants, including age, gender, nationality, address, household structure and parents' employment;
- those in the 12-17 age category were asked about their school, home life and social activities, as well as the details of looking after someone at home and finally the supports being provided or that should be provided;
- those in the 5-11 age category were asked about the details of looking after someone at home and how that impacted on their school life.

An experienced social science researcher conducted the interviews with the young carers. The interviewer was thus very mindful of the sensitive nature of the research and was able to provide vital additional information to the research team, not obvious or apparent from the recordings or transcripts. This included information about various contextual factors, such as the participant's mood and demeanour, and the space and facilities in the home.

### Agency interviews

The purpose of the agency interviews was to learn from managers, policy staff and front-line personnel about their own experiences of working with young carers. The research questions and the literature review informed the drafting of the interview schedule (*see Appendix 7*). The interviews were conducted by telephone at a time of the participants' choosing and each took approximately 30 minutes to complete.

The interviews were semi-structured and covered four areas or themes with interviewees:

- the role of their agency and their experience of working in the area of young carers;
- mechanisms that are, or should be, used to identify young carers;
- the impact of caring on young carers, both positive and negative, including age-inappropriate care and the relationship between caring and poverty;
- the supports and services that are, or should be, provided to young carers.

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<sup>8</sup> The 24 interviews that took place in the home included 2 interviews in a foster home.

## Analysis of information collected

As this is a piece of qualitative research, most of the primary data in the study is itself qualitative. The exception is the demographic data collected during the interviews. Although it was possible to analyse the quantitative data and to tabulate the findings, the majority of the data was examined using thematic analysis with the help of the NVivo software package for qualitative data analysis.

All interviews were formatted and then coded in NVivo. The use of NVivo allowed key themes to be identified, based on the research questions, and then the data from each participant was collated under these themes or headings. Consequently, it was easier to analyse the data in terms strictly relevant to the three research questions. The interview transcripts were first formatted under various headings that reflected the key themes of the study (*see Appendix 10 for a full list of the codes used when formatting the data in NVivo*).

## Ethical considerations and approval

The research was conducted according to strict ethical guidelines. Ethical approval was granted from the NUI Galway Research Ethics Committee in November 2008. Ethical considerations required that interviews with young carers could be conducted only after written consent had been received from both the young carers and their parents or guardians. Consent forms were accompanied by information sheets providing details of the aims of the study and what was involved in the interview process (*see Appendix 8*).

Children and young people deemed to be at risk of extreme emotional distress were not included in the study, in particular someone who had suffered a recent bereavement. The research team was aware that this did not mean that young people in need of assistance would not be encountered. Consequently, a Distressed Children Protocol (DCP) was developed, to be followed in the event of distress arising during an interview (*see Appendix 9*). The researchers were also bound by *Children First: National Guidelines for the Protection and Welfare of Children*, concerning appropriate behaviour when working with children and a protocol for circumstances wherein there is evidence of abuse (OMCYA, 1999, revised edition 2010).

Following the interviews, the research team sent 'Thank You' cards to all participants in the study. Included with the card was a token of the research team's appreciation in the form of a gift voucher to the value of €20. A leaflet containing details on the Carers Association was also included ([www.carersireland.com/youngcarers.php](http://www.carersireland.com/youngcarers.php)) with a Freephone information and helpline (Tel. 1800 240724), encouraging the young carers to be in contact if they would like to learn about the services, supports and advice the Association provides or if at any time they would just like someone to talk to.

Ethical considerations also required all data to be kept confidential. The information in the report was required to be presented in an anonymous format, with no names used and no participants identifiable. Once again, the researchers were bound by the *Children First* guidelines, meaning that if the researcher felt there was a significant risk to the child, this information must be passed on to the appropriate statutory authority. All information from the study will be securely stored in the Child and Family Research Centre at NUI Galway for 5 years after its completion.

## Learning points on identifying young carers and recruitment mechanisms

The relative lack of success in Phase 1 of the recruitment process of young carers was both a methodological challenge and a crucial finding in itself for the study. What this failure seemed to show was that:

- most agency workers, including those from carers' organisations and carer departments in the HSE, do not have direct contact with young carers;
- even for those agency workers and front-line staff who do have direct contact with families where there is a young carer, this strategy was largely ineffectual.

The recruitment of participants proved difficult because young carers are a 'hard to reach' population, meaning that they are to a significant degree 'invisible'. The invisibility of young carers presented the research team with recruitment difficulties in three different ways:

- Many professionals providing services to members of a family in need of care did not know that a young person within the home was a carer. Even when this fact was known, there were few if any services provided to young carers since carers' agency staff had little professional experience of working with young carers.
- The use of the term 'young carer' itself proved challenging. The reaction from agency staff and parents suggested that people associated the term exclusively with young people who are primary carers and/or provided intimate care. In addition, young carers may not necessarily define themselves in this way.
- Often, the phenomenon of young people caring was a sensitive issue and seemed to involve a stigma for both parents and their children, and for that reason they often were happy for the care work to be kept hidden. Young carers may have had feelings of shame due to the care needs of a family member, or they may have feared bullying from their peers; parents, in turn, may have wished to avoid the perception that they were subjecting their children to inappropriate caring roles and they may have feared a child protection intervention for such a reason (*see Chapter 2*). Due to the sensitivities surrounding the issue, many agency staff were reluctant to raise the subject with families, even where the presence of a young carer was known.

In an effort to overcome these challenges, the following conclusions were drawn:

- Referrals would *not* be generated simply through a written request to agency staff.
- In addition, researchers would have to do two things:
  - engage personally with a broad range of agency staff, including front-line staff, usually by phone, so as to develop trust and establish a relationship of researcher and 'gatekeeper'. Efforts were made to explain the concept of young carers; explain the nature of the data collection process and the importance of the research; and discuss the specific context in which the gatekeeper was working with or near young carers, since this would influence the type of contact that could or should be made;
  - employ a snowballing method, encouraging initial contacts to help generate further contacts.

Despite the relative success of Phase 2 of the recruitment process of young carers, it remained a time-consuming, lengthy and unpredictable process. This was because the three challenges relating to recruitment mentioned above still remained. Although the approach taken was a relatively successful response to those obstacles, it did not remove them as factors.

## Limitations of methodological approach

While the methodological approach of this study faced certain limitations, the research team has tried to respond effectively to those limitations. It was hoped to interview children and young people from a variety of backgrounds and caring situations, and the study was, by and large, successful in this regard. However, given that participants were recruited on the basis of the parent/guardian's consent, and following the engagement of the parent/guardian with a service provider or representative body, it was thought unlikely that the study would receive referrals from the most vulnerable children and young people, in particular those caring for a parent with a drug or alcohol addiction. This was reckoned to be the case since the parents of such children would be less likely to volunteer information about their family life or encourage outside interest in their affairs.

It was accepted that vulnerable young carers were less likely to be referred to the study by agency staff due to parental fears of child protection interventions. However, the research team did try to recruit young carers directly, without the mediation of agency staff, but no one in this category of vulnerable carer was willing to refer themselves to the study in response to the nationwide information and media campaigns. The research team attempted to address any possible resulting bias in the findings by taking on board the insights of agency staff in regard to the experiences of young carers in these situations.

Finally, the size of the sample is not a cause for concern since the original objective was to conduct an in-depth qualitative study with about 30 young carers. The problems encountered in recruiting even that number are, in themselves, a crucial finding of this study in respect of the 'invisibility' of young carers in the population.

## Summary

- To meet the objectives of the research, the study undertook empirical work with 26 young carers and 30 agency staff.
- The following working definition of 'young carer' was adopted for the purpose of this study:
 

A young carer is a child or young person under 18 years whose life is affected in a significant way by the need to provide care for a family or household member who has an illness, disability, addiction or other care requirement. This may include a child or young person who provides direct personal care or who takes on a supportive role for the main carer. A young carer may carry out domestic tasks or may provide general, intimate or emotional care. These needs may arise on a regular or on an occasional basis. There is therefore a continuum of caring and as a result the service requirements of young carers will vary. It is important to differentiate between a level of caring that has largely positive consequences and a level of physical or emotional caring that impairs the child's health, development or welfare.
- With regards to the recruitment of young carers, there was no sampling frame from which to draw a random sample of young carers in the Irish population. Young carers are, for the most part, not on the databases of HSE carer professionals or those of the non-statutory carers' organisations. In the absence of a sampling frame, the research team employed three closely related sampling methods: purposive, convenience and snowballing.
- There were two different phases of recruitment in relation to young carers. Phase 1 involved the following two-fold strategy: seeking referrals via agencies and seeking referrals via a nationwide information campaign.
- Despite extensive contact with a range of agencies and a nationwide information campaign – which involved the distribution of posters and flyers to all post-primary schools across Ireland and to a wide range of youth organisations – Phase 1 of the recruitment process generated just 6 referrals in total.

- In Phase 2 of recruitment, contacts with agencies, both in the statutory and non-statutory sectors, were expanded. The research team personally engaged by telephone all agency staff contacted, establishing good relationships with a broader range of key contacts and explaining the concept of young carer to them. A conscious effort was made to target front-line staff as possible gatekeepers. The research team also embarked on a regional and national media campaign in an effort to raise awareness about the study.
- This Phase 2 of recruitment was a vast improvement on Phase 1. A total sample size of 26 young carers was reached. Despite exhausting all avenues, therefore, the original objective – to conduct interviews with 30 young carers – was not achieved. The most important finding from this phase of recruitment was that the research team's personal relationships with the agency staff, acting as gatekeepers, was the single most influential factor explaining the attainment of referrals.
- Interview schedules for the young carers were designed specifically for two different age groups: 5-11 and 12-17 year-olds.
- The location for the interview was of the respondent's choosing and the time of interview at their convenience. The interview itself lasted no more than an hour and the respondent was free to end the interview at any time.
- To meet the objectives of the research, empirical work was also undertaken with 30 agency staff. The same three sampling methods (purposive, convenience and snowballing) were employed in the recruitment of agency staff. Many of the agency workers recruited to take part in interviews also played a role in the recruitment of young carers and the same rationales applied to both processes.
- The purpose of the agency interviews was to learn from managers, policy staff and front-line personnel about their own experiences of working with young carers.
- The NVivo software package was used to analyse the data collected from interviews with young carers and agency staff.
- Semi-structured interviews ensured sufficient flexibility to capture the variability and complexity of caring situations.
- The recruitment and interview processes in relation to both the young carers and the agency staff were conducted according to strict ethical guidelines. Ethical approval was granted from the NUI Galway Research Ethics Committee.
- The relative lack of success in Phase 1 of the recruitment process of young carers was a crucial finding. What this failure seemed to show was that (1) most agency workers, including those from carers' organisations, do not have direct contact with young carers; and (2) even for those agency and front-line staff who do have direct contact with families where there is a young carer, this strategy was largely ineffectual.
- The 'invisibility' of young carers presented significant challenges during the recruitment process because (1) agency staff often were unaware of the presence of young carers in a family; (2) the use of the term 'young carer' proved challenging, given that it was often associated exclusively with primary and/or intimate care; and (3) due to perceived stigma, the issue of young people caring was sensitive for both parents and their children, and for that reason both parents and children were often happy for the care work to be kept hidden.
- With regard to methodological limitations, the research team failed to recruit and interview children and young people of parents with drug and alcohol addictions. Given that participants were recruited through agency referral and on the basis of the parent/guardian's consent, it was thought that the parents of vulnerable children would be less likely to volunteer information about their family life or encourage outside interest from agency staff in their affairs.

# **4 FINDINGS FROM YOUNG CARERS' INTERVIEWS**

This study on young carers asked children and young people what they had to say about their experiences as carers. While similar research has been conducted in the past in other countries, this is the first occasion that a nationwide study of young carers in the Irish population was based on data gathered from interviews with young carers. The 26 young carers participating in the study took part in semi-structured interviews (*see Appendix 6A and 6B*). They were asked to give their perspective on their life at home, at school and with their friends; the tasks involved in caring for someone at home; the impact of caring on home life, school and their social life; and the supports they received and the supports they needed. The purpose of the interviews was to carry out empirical work with young carers on:

- ways in which other young carers might be identified by the statutory and non-statutory sectors;
- the extent to which caring impacts on their lives;
- ways in which young carers could be assisted.

The participants were able to understand the interview questions and to respond in detail to them. However, not unsurprisingly given the young age of some of the participants, not all questions were directly answered or answered in full.

**NOTE: All names used in this chapter are pseudonyms. Each participating young carer was given an identification number and letter, ranging from P1 to P26. Quotes from participants are given throughout; they have been subject to minimal editing in order to retain the tenor of the comments made.**

## Sample profile

### Sources of referrals

Table 1 shows the routes through which participants were referred to the study. The number of referrals generated from the non-statutory sector was more than three times that generated through the statutory sector. In most cases, staff from both sectors were not providing a service to the young carer, but instead had knowledge of the young carer through providing services to someone else in the home.

**Table 1: Sources of referral for the study (n = 26)**

Sector	No. of young carers
Statutory sector	6
Non-statutory sector	20

### Gender, age and ethnicity

Of the 26 participants in the study, 7 were male and 19 were female (*see Table 2*). The average age of participants was 13 years. Two of the participants were non-Irish nationals. All the young carers were fluent English speakers. The research team was unable to include participants from the Traveller community despite gatekeepers making initial contact with three families.

**Table 2: Age and gender of participating young carers (n = 26)**

Age	Male	Female	Total
5-11 years	2	8	10
12-17 years	5	11	16
<b>Total</b>	7	19	26



## Household structure and person cared for

The relationship of the person with care needs to the young carer was of particular interest to the study because this would have an important bearing on relationships within the household, including relationships between parents/guardian and their children, and relationships among siblings. As Table 3 shows, 16 of the young carers lived in two-parent households and 10 lived in one-parent families. Most young carers (15) cared exclusively for a sibling(s), while 5 cared exclusively for a mother and 1 for a father. In other families, 2 young sisters cared for both their father and their brothers; another 2 young sisters cared for their grandmother; and one young carer cared for both her mother and her father.

**Table 3: Association between household structure and person(s) cared for (n = 26)**

Person cared for	Young carer in a one-parent family	Young carer in a two-parent family	Total
Mother	5	0	5
Father	1	0	1
Both parents	0	1	1
Sibling(s)	0	15	15
Grandparent	2	0	2
Sibling(s) and Father	2	0	2
<b>Total</b>	10	16	26

All the young carers caring exclusively for a mother or exclusively for a father lived in a one-parent family, and all the young carers caring exclusively for a sibling(s) did so in two-parent families. One exception to this pattern was the single young person caring for both parents in a two-parent home. In some households, more than one person was in receipt of care, and in some cases there was more than one young carer interviewed in the household.

Household structure is an important factor influencing the types of supports available both to the young carer and also to the person in need of care. One situation that is most obviously of interest is where a young carer is caring for a parent in a one-parent family. By definition, these young carers will be the 'primary carers' in any such household (*see below*, 'Primary and secondary carers'). At the same time, primary carers can be found in other household structures as well. What is more, the fact that a young person is a primary carer says nothing about the types of tasks he or she is performing, the number of hours spent caring or the impacts of caring on the carer.

## Paid employment in the household

Employment is another potentially important factor influencing the support available for young carers and for the people in need of care. Employment influences the amount of income available in the household to help with caring and also the time available to adults (as opposed to their children) to perform caring tasks. At the same time, often an adult's ability to hold down employment will be affected by their need for care or their own caring responsibilities.

As Table 4 shows, there were 8 young carers living in households without any adult in paid work. These were all one-parent households, where the parent was in receipt of care from the young carer (in one of these households, children also were in receipt of care). In addition, there were 10 young carers living in households that contained only one adult in paid work; these were all two-parent families. In only one such case, the parents were in receipt of care and in this household both parents were being cared for. In all other cases, the people being cared for were siblings.

A total of 7 young carers lived in households that contained 2 adults in paid work. In none of these households were the parents in receipt of care: in all instances bar one, the young carers were caring for siblings; the exception was a household where two sisters cared for their grandmother. In one household, both parents were retired and the young carer cared for a sibling with autism.

**Table 4: Association between paid employment in household and young carers (n = 26)**

<b>Paid employment in household</b>	<b>Young carer in household</b>
2 adults in paid work	7
1 adult in paid work	10
No adult in paid work	8
Retired	1

### Rural or urban locations

The young carers interviewed lived in both rural and urban locations (*see Table 5*). Rural locations included homes in remote townlands and small villages. Urban locations included homes in Galway city and Dublin city, and in a number of towns throughout the country. Within the towns, the homes classified as urban were located either in the town centre or on the outskirts of the town but within walking distance of the centre. In terms of geographical spread, the young carers interviewed came from throughout the country, with a concentration in the west of Ireland (*see Appendix 11*).

**Table 5: Rural or urban location of household (n = 26)**

<b>Location</b>	<b>No. of young carers</b>
Rural	11
Urban	15

## Nature of care

### Length of time caring

As Table 6 shows, the majority of participants (19) had been caring from below the age of 9. Many responded that they had been caring for as long as they could remember, or from the birth of the sibling in need of care. Most participants in this situation also reported that caring began gradually and imperceptibly, and that to begin with the range of tasks were few and the level of responsibility low.

**Table 6: Age at which caring began (n = 26)**

<b>Age at which caring began</b>	<b>No. of young carers</b>
Below 5 years	14
5-8 years	5
9-12 years	5
13-15 years	1
16 years and older	1

In most cases, caring could not be traced back to an explicit agreement between the carer and the person cared for and/or parent. Even a young person caring from the age of 16 for his father did so without much in the way of a conscious or explicit agreement:

- Interviewer: Were you asked to do it or was it just obvious that it needed to be done, or did you have to talk to your Dad about it?
- P2: I said to him, 'Sure'. You just take it for granted. You have to help him, you know. It's not something you ask him, 'Do you want help?'
- Interviewer: Yes, so you just took over the kind of things that he wasn't able to do for himself?
- P2: Yes. Well, my sister helps as well, so it's grand.

One reason why the situation of young carers causes concern for some observers is that in some cases the caring role is not completely voluntary.

In this study, a difference emerged among families in regard to the amount of information shared between parents and the young carer, and therefore the extent to which the young carer's participation could be said to be 'informed'. In some families, the young carers had received little or no information about the condition or illness concerned from either professionals or parents. In contrast, young carers in other families were very much included in conversations with parents and/or professionals, and reported feeling that they could go to someone for advice and support.

### Reason why help is needed

So far, the person cared for and the household structure has been discussed. Another important factor shaping support for the young carer and the person in need of care is the reason why care is needed. Each condition, disability or illness has its own consequences for those providing care. It can influence the types of tasks to be performed, as well as the services that are needed, and can have a profound influence on the relationship between the carer and the person cared for.

In this study, the people in need of care had a range of care needs. These were classified as behavioural or learning difficulties, combined physical and intellectual disability, physical illness, mental illness and sensory impairment.

Although 26 young people participated in the study, they cared for a total of 28 people. In some households, more than one young person was providing care, although in some cases young people were caring for more than one person. As Table 7 shows, many of those receiving care had a combined physical and intellectual disability (6), although the most frequently occurring conditions were behavioural difficulties (e.g. autism) or learning difficulties (13).

**Table 7: Reason why care is needed (n = 28)**

Type of condition	No. of people requiring care
Behavioural or learning difficulties	13
Combined physical and intellectual disability	6
Physical illness	5
Mental illness	3
Sensory impairment	1

### Primary and secondary carers

A further issue to explore is the level of care undertaken by the participants. For the purpose of this study, primary and secondary carers have been defined as follows:

- a **primary carer** is the predominant carer within the home;
- a **secondary carer** helps the primary carer to provide care to a household member.

Most participants in the study (17) were secondary carers, although a substantial minority were primary carers (9). All secondary carers cared for a sibling(s). All primary carers were caring for a parent(s) (although 2 primary carers also cared for their siblings). In becoming a primary carer, a young person takes on a considerable level of responsibility within the home. In some situations, the young person takes on caring roles typically undertaken by an adult.

A 15-year-old carer, who helps her mother with back problems, was asked how long she had been the primary carer for her mother:

- P1: For as long as I can remember. When I was 5 or 6, she broke her leg – we had to help her with her cast – she used to have to wear a cast.  
Interviewer: And that wasn't related to her back?  
P1: No, I don't think so. I was very young at the time.

When asked whose idea it was that she care for her mother, she replied:

- P1: Don't know – it's just part of life.

As Table 8 shows, most young carers were secondary carers and this was the case for the male and female participants. In most cases, secondary carers cared for another sibling. In contrast, most primary carers cared for a parent, although 2 primary carers within the one household cared for both their siblings and their father.

**Table 8: Association between gender and level of responsibility (n = 26)**

Gender	Primary carer	Secondary carer
Male	3	4
Female	6	13
<b>Total</b>	9	17

Young people became primary carers often as a result of some major disruption to the household. In one case, the young carer's mother had passed away and, as a result, he became the primary carer for his father. In another situation, a young girl cared for her mother after the breakup of her parents' relationship. In yet another case, 2 sisters cared for their father and their 3 siblings in a household where the mother was absent. Primary carers were also found in two-parent households: in one case, a young girl was caring for both her father and her mother.

## Supports provided and wanted

The young carers were asked a general question about the supports they received, if they would like additional support and also if there was anything that would make their lives easier. It should be noted that the question on supports was only asked of the young carers in the older age group, those aged 12-17 (see *Appendix 6B*). Also, in some instances the young person did not have a very clear knowledge of the supports received in the family and this was particularly true of income support. For these reasons, the data presented here cannot be said to be a comprehensive list of all supports actually received by the young carers and their families.

The most frequently reported form of support received was home help. Young carers also reported that they were supported by their peers and through the receipt of income (disability allowance to the care recipient or carer's allowance to the adult primary carer), as well as various forms of treatment for the person being cared for (including education and medical treatment) and respite care.

On the kinds of support needed, young carers most frequently requested additional home help, even though this was the most frequently reported support actually provided. Following that, young carers expressed wishes for more and better treatment, respite care, advice and transport.

### **Income support**

Most of the participants were unable to give clear and informed answers on income support received by the family, such as a disability allowance or a carer's allowance. This was not surprising since none of the young carers had taken on extensive responsibilities over the family's finances. This was the case even for a 16-year-old carer who had many responsibilities arising from the care needs of his 3 brothers with intellectual disabilities:

Interviewer: OK, so does your family get any support to cover the costs of services or anything for helping with Mark and Brian?

P19: I tend not to look into that or know ... Mark gets support in school and, you know, he has some home help and stuff like that. But otherwise, I don't really get into that side of things.

### **Home help**

Most young carers said that home help was a great benefit to the family and most believed that it lightened their own responsibilities as carers. A 16-year-old carer who, along with her sister, cared for her 3 brothers and father did say that the family needed more home help, even though she was willing to carry on with her caring responsibilities:

Interviewer: Is there any more support that you would like?

P16: Just knowing that there is more support would be nice, not that we necessarily need it, but ...

Interviewer: Yes. And more [home help] hours, or would that bother you? Yes?

P16: Yes. That would be a big help actually. I wouldn't have to do half as much.

### **Treatment**

Services were also provided outside the home and the young carers made reference to various forms of treatment the person being cared for received, in particular medical treatment and education. What is clear is that the young carers felt that these services were an absolutely necessary part of their families' lives. This was certainly the case for educational services provided to a young girl with autism. Her 10-year-old sister felt that special needs assistants in school were a crucial resource and that the loss of this service for a time was a big blow to the young sister:

Interviewer: So if there were any other support that your family could get for Susan, what do you think would be helpful?

P21: Her own little room for her to do all the subjects in.

Interviewer: Her own room in school?

P21: Yeah, in school. Like she used to.

Perhaps unsurprisingly, many young carers wanted more than anything for an effective treatment to be found for their ill or disabled relative:

Interviewer: If there was anything else that could happen that would make your life easier, what do you think that would be?

P1: My Mam be better, I suppose.

### **Respite care**

Many of the families were receiving respite care. This was seen as a valuable service as well because it lifted the responsibilities of care temporarily and in that time the rest of the family was able to travel and to spend time together. However, the length of time in respite was limited and in any case families usually did not want to go very far in case they had to be called back as a result of some emergency. This was the case for the family where a 10-year-old carer helped with her younger sister with intellectual disabilities:

Interviewer: And when you are going on holidays, for how long would you go? Or how long would she go into respite then?

P20: She would go for 4 days, no 5 days.

Interviewer: Right.

P20: See, we would only go around Ireland because if we went abroad, she would ... if something ever happened to her.

One 14-year-old caring for her brother with intellectual disabilities was clearly aware of the issue of the availability of services. She said that demand for respite care had increased and that as a result less respite care would be available for her brother. It was also apparent that she felt that her family was in competition with others for a scarce resource:

Interviewer: Is there any more support that you would like? Anything you think would be useful?

P23: I'm not sure. I think just maybe if we got more respite. Because they have cut down an awful lot.

Interviewer: Oh, have they really? And is that recently?

P23: Yes, recently ... because more families are kind of demanding more nights, so they have to cut down on some people.

### *Changing needs and flexible services*

Some young carers reported that, although in the past they had needed services, their need was not as great now. One 15-year-old carer told how in recent years support from a non-statutory organisation had helped make their home wheelchair-accessible for her mother. Since she no longer needed to provide as much help with her mother's mobility, this single intervention had radically changed her caring tasks. As a result, the need for further formal services was greatly reduced:

Interviewer: So would you like more support?

P1: Not particularly now, because, you know, it's a lot lighter. But when I was a lot [younger], I would have loved some support.

Young carers were quick to say when they felt that formal supports were not sufficient and in such situations they reported feeling neglected by the service providers. In one case, a 15-year-old carer, helping with her sister who had intellectual and physical disabilities, felt that there was no support at all and that the family was being left to its own devices:

Interviewer: So would you like to see her getting more support or ...?

P11: Yes. Because there is only, there is no one helps, like, it's only us.

Interviewer: Yes. So there is never anyone to give you all a break together as a family.

P11: No.

One 14-year-old who cared for her mother with a physical illness described how gaps sometimes appeared in their home help support and that such shortfalls would happen without warning. As her mother needed constant care all day long, including intimate care, the young carer reported that when at school she would worry about whether her mother had been left alone. On some occasions, she returned home to find that her mother had been left uncared for and this was obviously a cause of distress for both her and her mother:

P9: Paula [home help worker] goes around 2.30 and she [mother] is getting help then lately from after 2.30 till 5 o'clock on Thursdays and Fridays. But now she can't come any more. So when you're on summer holidays it's not too bad, but when you're in school ... Like, I used to come home and I'd have to change her because there was no one here.

### *Friends and peers*

Friends were another source of support to young carers. One 18-year-old carer, caring for his younger brother with intellectual and physical disabilities, relied on a close friend in a similar situation. Although this young carer had both his parents and 2 other brothers with him at home, he highlighted how important it was to be able to spend time with and chat with a friend who could understand the caring situation:

Interviewer: So would you say your friends understand and help out with Kevin? You were saying one friend has a ...

P10: Yeah, his name is Jonathan. He knows exactly how it is. My other friends, being real, I don't think they take an interest in it, but that's their problem, like.

Interviewer: Yeah.

- P10: But Jonathan knows exactly, like, how it is.  
Interviewer: So the two of you would talk about it?  
P10: Yeah.  
Interviewer: And what age is the child in his family?  
P10: I think he's a year older than Kevin. We talk about that his brother – his brother hits people a lot. And then Kevin has tendencies to shout a bit as well, and his brother is a bit quieter. We talk about stuff like that.  
Interviewer: Differences and similarities.  
P10: Yeah, just like, not comparing but just talking about it.

Even those young carers who had friends they could rely on also identified friends that were not supportive or not understanding. Indeed, they often drew a very sharp and clear line between the two sets of peers. This was the case with a 10-year-old girl caring for her sister with intellectual disabilities:

- Interviewer: And I suppose you have learnt a lot about helping somebody with special needs and things, where your friends wouldn't?  
P20: I would know what to do, and all that. One of my friends hates – well, they don't hate – Isabel; they are just afraid of her because, see, Isabel likes them, but when she sees someone she likes and that, she goes over and hits them as a greeting.  
Interviewer: Oh right, and they don't understand or they don't like that?  
P20: They do understand, they just don't like it.  
Interviewer: Right.  
P20: And one of them said, 'Only bring me over when she is in respite'. I said, 'Right, OK'.  
Interviewer: No! So would your friends, do you have any friends who kind of understand how Isabel's condition is or that you can talk to about it?  
P20: Yes, one of them ... she really understands her.

Another frequently mentioned form of support to young carers comes from peers. For example, youth organisations can provide advice and information to young people concerning issues that are important to them, including caring, and some of the participants in the study reported such contact. Mentoring is another form of support: one of the participants was being supported by the 'Big Brother Big Sister' programme run by Foróige. Another crucial support is provided by clubs and associations. Some young carers reported that their participation in the local GAA club, for example, was an important social activity for them. Indeed, many young carers reported that they were sorry not to be able to take part in or attend matches as a result of their caring responsibilities.

### Teachers

Teachers were another very important source of support for many of the young carers, with 9 of the 26 carers interviewed receiving some form of support from their teachers. In some instances, teachers provided extra help with school work. In other cases, the teacher understood the carer's situation and took this into consideration when the carer needed extra time or help with work:

- Interviewer: And do you get any extra help from teachers?  
P15: Well yeah, and there's an odd teacher too that knows that there's something wrong with you. They'll call you back then to the class and ask you.  
Interviewer: And would you tell them? As you go into different teachers, do you explain or do you tell the Principal?  
P15: Yeah, if there's a problem, we tell the Vice-Principal because she knows exactly who is at home and what goes on.  
Interviewer: So if you miss days or anything, it would be her that you'd talk to?  
P15: Yeah.



However, a substantial number of carers reported that no one in their school was aware of their caring role at home and they received no extra help or guidance from school:

Interviewer: And would you get any extra help from teachers?

P8: No, not a lot of people know.

### *Advice and information*

Advice was another form of support that was asked about. Some families made sure that advice and information was made available to their young carers or the parents themselves provided this information and advice. A 17-year-old, caring for his brother with intellectual and physical disabilities, said that in his family the information was shared between everyone; it was not just a matter of adults imparting information to the children:

Interviewer: And do you get any advice or support in terms of helping to look after him?

P17: Outside the family?

Interviewer: No, both.

P17: In the family, well yeah, you would, yeah.

Interviewer: So that would be from either or both of your parents, would it?

P17: The whole family really. Just any observations that you might just say to them, 'Oh yeah, I suppose that's right'. You know.

Interviewer: Yeah.

P17: We wouldn't do it formally, just if it cropped up.

Interviewer: Yeah, and from outside? Have you ever spoken to a professional about it?

P17: No.

Sometimes, formal advice and support was combined with peer support groups. This was the case for a 16-year-old who helped care for his 3 brothers with intellectual disabilities:

Interviewer: Would you ever get any advice or support in terms of how you would help with them?

P19: Well, my parents offer – tell me – different ways how to react and cope with Mark, do you know ... I've been to a group before where I have been [with] other people my age that have brothers and sisters with autism or Asperger Syndrome and, you know, in those groups I've learned how to deal with things as well.

Interviewer: OK, and are they through the Asperger Association or something like that, or how did you come to those?

P19: Yes, something like that. Now, I don't know exactly the name, but they are something to do with it anyway.

Interviewer: And have you ever been spoken to or talked to, I don't know, by a doctor or psychologist or professional of any sort?

P19: Yes, like once or twice, do you know, just about that actual fact[s].

Interviewer: And would you have found that helpful?

P19: Yes. Quite helpful now.

In other families, the young carer expressed a wish for greater advice and information. There was no information available from the very start for one 17-year-old caring for her brother with autism:

Interviewer: So do you think you would like more support or is there more support that would help your family?

P5: Yes.

Interviewer: So what do you think would help?

P5: Help to understand it more and helping you deal with [it] ... You never get that from the start.

## Caring tasks performed

### Caring tasks and those cared for

So far, the kinds of formal and informal supports that young carers receive and what they would like to receive has been looked at. However, this provides only one part of the story. It is also necessary to understand the kinds of caring tasks young carers perform. While young carers provide a vital service to those in need of care, in some cases children and young people are doing the kinds of job that many would consider are, by and large, inappropriate for their age.

Participants in the study reported performing a wide range of tasks. For the purpose of this study, the tasks have been categorised as either domestic, general, emotional, child care, intimate or other:

- **Domestic tasks** included housekeeping work, such as cleaning, cooking, gardening, washing, picking up after others, putting out rubbish and other tasks.
- **General care** included tasks associated with the need for care, such as helping with medication, mobility, feeding and doctors' appointments.
- **Emotional support** included observation of moods and attempting to alter or modify or support moods.
- **Child care** involved taking responsibility for a sibling, including child-minding and playing.
- **Intimate care** included bathing, dressing and toileting.
- **Other** tasks included such varied responsibilities as reading, watching television, exercising and playing music.

Table 9 records the number of young carers who reported performing specific caring tasks. Multiple responses were allowed and young carers performed many different types of caring tasks, although all 26 participants performed domestic tasks.

**Table 9: Caring tasks performed (n = 26)**

Caring task performed (multiple responses)	No. of young carers
Domestic tasks	26
General care	19
Child care	17
Intimate care	16
Emotional support	7
Other	7

Table 10 records the association between conditions, disabilities and illnesses of the people cared for, on the one hand, and the caring tasks performed by young carers, on the other. It should be remembered that many carers performed more than one kind of task; that some of those in need of care had more than one condition, illness or disability; and that some of those in receipt of care were cared for by more than one young carer participating in this study.

Where intimate care was provided, the recipient was most likely to have a learning or behavioural difficulty (6) or an intellectual and physical disability (7). Emotional support was provided where there was a learning or behavioural difficulty, physical and intellectual disabilities, and mental illness.

**Table 10: Association between caring tasks and illness/disability/condition (n = 26)**

Caring task performed (multiple responses)	Learning or behavioural difficulties	Intellectual and physical disability	Physical illness	Mental illness	Sensory impairment
Domestic tasks	10	7	4	4	1
General care	6	6	3	4	0
Child care	6	7	2	1	0
Intimate care	10	7	0	0	0
Emotional support	4	1	0	2	0
Other	3	1	0	2	1

There was only one instance of a sensory impairment in the study. A young girl cared for her mother whose hearing was impaired. The task performed by the young carer was to translate for her mother using sign language, in particular in social situations with friends of the mother.

Concerning emotional support, a 10-year-old girl told of the need to remain 'positive' with her sister, which she found particularly difficult. An 11-year-old carer talked about the need to pacify her sister, in particular in public spaces:

Interviewer: OK, and do you find it hard or do you find it easy?

P5: Both sometimes ... [it depends on] what you are doing. Sometimes in the shop she does, she kind of, she doesn't like, she likes big open spaces. She doesn't like to be – you know, she gets a bit claustrophobic.

Interviewer: Oh yes, OK.

P5: And you have to take her outside and walk her up and down.

A 9-year-old girl helped care for her mother, who suffered from a mental illness. The young carer took responsibility for monitoring her mother's moods and offered important emotional support whenever her mother suffered a relapse in her condition:

P26: And I always make sure that she's happy because when she gets upset, she'll cry. And, like, when I'm with my friends, she'll stand – like, my friend's house is over there and my Mum will stand right beside the field there. And she'll stand crying and she'll call me and then I'd always have to comfort her. So I try to make her happy.

Interviewer: And how would you do that?

P26: Well, kind of comfort her and call her friends and tell her, 'It's going to be OK'.

Domestic tasks were performed by all the young carers. In most cases, they also performed other kinds of tasks, in particular intimate and/or general care. In a small number of instances, however, the role of the young carer concentrated on domestic tasks. Three young people who were primary carers (2 boys and 1 girl) performed domestic tasks for the most part. The extent of the domestic duties was significant in terms of the wide range of tasks performed and the time involved in undertaking them.

Participants for the most part were involved in general care tasks from an early age. Some of the younger carers, as young as 10 and 11 years of age, reported helping with medication, while others as young as 14 and 16 reported that they would attend medical appointments with the care recipient. However, others were performing tasks that were more complex, demanding and unusual for children and young people of their age. One teenage girl who cared for her mother suffering from MS would help her at meal times:

Interviewer: Does she need help with eating?

P9: Yeah, her hands, her right hand doesn't work very well and the left hand isn't great. So, generally I'd feed her, like. She'd be able for the first while and she'd do it herself, but after that I'd stay and feed her.

The same young carer also helped with telephone calls:

Interviewer: Would you make phone calls for your Mum if she needed?

P9: I would, yeah, because she's not very good with her speech.

## Intimate care

In the literature on young carers, intimate care is an important and controversial topic. The category of intimate care includes dressing, bathing and toileting tasks, each of which is explored below.

### Dressing

In some cases where a young carer reported helping with dressing, it might be inaccurate to say that the tasks involved were 'intimate.' This was the case with one young girl who helped her grandparent, suffering from Alzheimer's Disease, to put on her coat when going out and also another young girl who would tie her brother's shoe laces. Nonetheless, in some families the young carer began to help with dressing at a very early age. One 11-year-old girl explained her role in helping to dress her sister who has autism:

Interviewer: And in terms of helping to look after Avril, do you sort of help her to get dressed or is she able to do that herself?

P6: Well, she can't do that herself. We help her, you know.

Interviewer: So would that be every day?

P6: Yes, because she hates white colours, you know, pale colours. She likes big, bold – like red and blue and primary colours. She won't wear white socks or anything. They have trouble picking clothes for her because she might like blue today and tomorrow, and then yellow the next day, green ...

However, the dressing tasks of other young carers were more unequivocally 'intimate' in nature. For example, a 10-year-old young carer helped with dressing her sister who suffers from autism. Her sister needed to be helped to dress every day and mostly this would be done by their mother:

P20: Well, in the mornings when we are going to school, or anytime.

Sometimes she doesn't get dressed for Mammy, so I dress her.

Interviewer: And would that happen often? Would that be something you do quite a lot?

P20: Well, the last few days she rather Mam do it. But her medicine, and her socks, sometimes she wants me to put them on.

Young female carers were providing this type of care to their brothers as well. A 16-year-old girl, caring for her 6-year-old brother with intellectual and physical disabilities, also helped him to dress:

Interviewer: And does Dave need help getting dressed?

P22: He does.

Interviewer: And would you be involved in that?

P22: Yeah, I'd just help get him dressed properly, I suppose. He does it occasionally by himself, but he gets things backwards and so I'd help him get things on the right way, so there are no labels sticking out the front – collars and stuff.

In a number of cases, a young carer helped a parent to dress, as, for example, when the parent was immobile as a result of a physically debilitating illness. A 14-year-old girl in this situation explained that, although her brothers were also expected to help dress their mother, the responsibility usually fell to her:

Interviewer: Do you need to help your Mum? Does she need help getting dressed?

P9: Yeah. I'd probably do that as well. She does call us in the morning, but I'd usually be the first to get up. Or when she's going out to the pub, I'd get her ready myself.

As we shall see below, this young carer also helped her mother with bathing and toileting, and this was the case with a number of other young carers.

### **Bathing**

The task of bathing meant different things in different situations. Some carers had the responsibility of 'monitoring' at bath time to make sure a sibling did not fall over or cause damage. This was the case with a 16-year-old girl caring for her 6-year-old brother with intellectual and physical disabilities:

Interviewer: And does he need help with showering or bathing?

P22: Maybe to wash his hair, but he can bathe himself.

Interviewer: And would you do that?

P22: It's usually my Mum, but I get the things. We have the shower gel hidden just because he doesn't get carried away with it. I bring it in for him when he wants to shower.

Much the same was reported by a 14-year-old girl caring for her 11-year-old brother with intellectual disabilities:

P23: If he's in the bath, I'll always go in and maybe wash his hair and just sit with him in the bath so he doesn't fall or anything.

Another young carer, an 11-year-old girl caring for her sister with autism, indicated how infrequent the occurrence of this responsibility was for her:

P6: Yes, I help once or twice a year.

Some took full responsibility for the whole bathing process. A 16-year-old carer helped his younger brother to bathe, just as he had done in the past with another young brother, also with intellectual disabilities:

Interviewer: So helping with showering or bathing or any of that kind of thing?

P19: Yes, with Brian, yes. But Mark is able to ... he's got to the age now where he is well capable of looking after himself that way, But Brian, yes.

The task of bathing is significant, in part because it can be a physically demanding job, especially when a child is caring for an adult or for a heavy sibling. This was the case with a 15-year-old girl caring for her mother with back problems and also a 15-year-old girl caring for her 11-year-old sister with intellectual and physical disabilities.

### **Toileting**

Young carers also took responsibility for toileting. A 14-year-old young carer helped look after her grandmother suffering from Alzheimer's Disease; in this case, the young carer had to make sure that her grandmother did not get confused when finding the bathroom. An 18-year-old male carer looked after his younger brother with intellectual and physical disabilities. He emphasized that, when using the bathroom, although his brother was able to start, often he would need help at some stage:

P10: He always just stands at the potty, like. Sometimes he wets his nappy, but if he's not, he'd sit down at the toilet and he'll stand up and he can do to some extent the pants himself. We'll give him a hand then.

A 10-year-old girl caring for her 6-year-old brother with Down's Syndrome explained that:

P12: He's able to start himself, but usually pulling up his trousers or something after, sometimes if Dad is busy, I'll go and do that.

A 14-year-old girl, caring for her 11-year-old brother with intellectual disabilities, was involved in both dressing and toileting:

Interviewer: And you said that he's not toilet-trained, so he wears a nappy, is it?

P23: Yes, 'pull-ups'.

Interviewer: And do you help him with that?

P23: Yes, I'd help him with that. Usually, when I'm getting him dressed during the day or anything, I'd just change his pull-up if it was ...

In some cases, the young carers also gave this sort of help to a parent. A 15-year-old caring for her mother with a bad back reported that things had improved greatly in recent years. While in the past her mother needed help using a bed pan, since then the house had been renovated to include a bathroom that is wheelchair-accessible. However, another young carer had considerable responsibilities in this area when caring for her mother with a physical illness. The young carer would help lift her mother in the bathroom, both in the home and in public toilets. Her mother enjoyed going out to socialise in their local pub, but this was an obvious source of concern and worry for her daughter who would accompany her:

P9: When she goes up to the pub, the local pub she likes to go there, but they've a really bad toilet. Like, it's tiny and there has to be 2 or 3 of us there. We'd only stay for about an hour because I'd be afraid she would need to go and I wouldn't be able to bring her, not enough room or anything. But when there's a disabled toilet, usually I'm fine. There's a lot of room in them, like.

Also, this young carer was not eager to continue providing care in this respect in the future:

P9: I'm trying to convince her to get the bag for going to the toilet instead of having to bring her all the time. It would be the worst part of it, like, having to lift her onto the toilet and not getting there on time and things ...

It is also clear that some parents made a great effort to shield their young carers from toileting duties. This was the case with a 17-year-old carer who, although he was involved in the dressing and bathing of his younger brother who had intellectual and physical disabilities, nonetheless had been spared what obviously in his family were thought to be inappropriate responsibilities:

Interviewer: Does he need help going to the toilet?

P17: Well, he's got nappies.

Interviewer: And would you ever be involved in changing?

P17: So far I've dodged it.

## Impacts of caring on young carers

Not every participant in the study provided reports on positive and negative impacts in every relevant area. This can be explained by the young age of some of the participants and the semi-structured nature of the interviews.

The findings so far have concerned the kinds of tasks performed by young carers, paying particular attention to intimate care, and also the different levels of responsibility, i.e. whether or not the child or young person was a primary carer. What still needs to be addressed are the impacts of caring on the young carer. The following discussion examines the general impacts of caring, followed by the more specific impacts of certain tasks, such as intimate care, and impacts on primary and secondary carers.

The reader should bear in mind that many respondents had both negative and positive things to say about the impacts of caring on their lives. Sometimes they reported both positive and negative impacts in a single area. For example, a young carer may say that he or she was helped with school work and had good attendance at school (a positive educational impact), but also that he or she often felt distracted while in school (a negative educational impact, attributed to the carer's caring role). A further point to note is that, in many cases where a carer made a positive or negative report in some area, it was not clear that the caring role was the perceived cause of these impacts. However, the coincidence of the positive or negative report and the caring role was itself considered a significant finding.

## General impacts

Table 11 shows the impacts of caring in various different areas. It should be noted that although many of the participants indicated that one consequence of their caring role was that they felt 'closer' to the person cared for, some of the participants (at least 5) who did not report a positive impact here also did not indicate a negative impact either. In other words, while some young carers said they did feel close to the person cared for, they did not feel any closer to them than they did to their other relatives. Others reported that they believed their friends felt just as close to their own relatives as they (the young carers) did to the person cared for.

**Table 11: Young carers reporting negative and/or positive impacts in various areas (n = 26)**

Area of impact (multiple responses)	Negative reports	Positive reports
Social	9	15
Education	20	9
Physical	10	0
Emotional	15	13
Maturity	1	19
Closeness	3	12

## Physical impacts

Caring can be a physically demanding role. In some cases, the person cared for would lash out violently at the young carer. A 10-year-old carer had to deal with the occasional biting and kicking of her 14-year-old sister with intellectual disabilities; the same was the case for a 10-year-old caring for his 5-year-old brother with Asperger Syndrome. Carers also reported being tired and not sleeping enough.

In one situation, the young carer indicated that the physical exertion of caring was straining her back. This 14-year-old talked about the physical effects of lifting her mother:

P9: We have hoists, but when it comes to going to the toilet I'd probably lift her because it takes too long and by the time, it's too late, like. Kind of, it does hurt my back sometimes, but like I try and bend my knees a certain way. I don't know. I want to get there on time, like, but the lads [her brothers] do help me sometimes.

Some conditions may be hereditary and so a young carer may inherit a condition from his or her parent in need of care, or fear that this may happen. Further, the physical strain of caring may bring on significant symptoms in the young carer. One of the participants was a 15-year-old caring for her mother with back problems. The young carer helped with her mother's mobility, helping her dress and use the toilet. The young carer reported that she was currently absent from school with her own back problems, although the family was of the view that this problem derived from her father's side of the family.

## Education

Concerning the effects of caring on the young carer's education, in some cases the negative impact seemed clear. One 17-year-old carer said that she had left school in the previous few months. She did not explain why that was the case, but noted at other points that her teachers had not been aware of her brother's autism, that she had felt bored in school and that when in school she would often be worried about what her brother was doing at home. She shared a room with her 11-year-old brother and explained that 'he used to get at my make-up and put it all over my room, so I worried about that' (P5).



Some reported feeling distracted and worried at school. This was the case for a 16-year-old that cared for his 3 brothers with intellectual disabilities:

- Interviewer: And if you are in school, or anywhere else for that matter, would you ever be sort of distracted or concerned about, you know, if there was ...?
- P19: Yes, sometimes. Like, it depends how bad, you know, Mark has or Brian has a tantrum or is really worked up and causing the family strife or whatever, you know. That can ...
- Interviewer: Kind of be on your mind?
- P19: ... can be on my mind and I can get somewhat worked up or stressed about that in school.
- Interviewer: And would that be a kind of regular thing or just ...?
- P19: No, now and again, like, you know.

Some were absent from school whenever there were crises at home as a result of the need for care. In those households, education came second to the young person's caring role. As one 16-year-old, caring for her brothers and her father, said:

- P16: We both stay at home when we are needed.
- Interviewer: Yes.
- P16: Because it's not nice sitting in school worrying about something either, do you know.
- Interviewer: So you wouldn't sort of take turns or something? You would both, if there was something going on?
- P16: Yes, we both sort of ...
- Interviewer: Yes.
- P16: School would be the last thing.

In other cases, the impacts on education seemed to be both positive and negative – participants talked of their positive experiences and the help they received, on the one hand, but also about their absences from school or being distracted in school as a result of their caring work. This was the response of a 10-year-old that cared for her sister with intellectual disabilities:

- P21: I actually love my homework ... Sometimes I can get stressed from my homework because, you know, my head's not clear and I'm not in the right mood and sometimes I do it in the morning when I'm awake properly.

## **Bullying**

Young carers were asked whether they had been bullied at school and if so whether they felt the bullying was a direct result of their caring role. Many reported having been bullied or teased at some stage, but that they felt it had nothing to do with their caring role. However, a 14-year-old caring for her brother with autism said she was bullied 'once or twice':

- P23: It wouldn't have been severe or anything like that. It would just be, 'Oh, you have an autistic brother, don't you?' And that would just kind of be the end of it.

An 11-year-old was teased some of the time, but:

- P6: ... they don't really bully because my Mum gives out to them.

## **Social impacts**

Young carers were asked about their social activities and friendships. In some cases, due to their caring role young carers did not have time to spend with friends or more specifically in extra-curricular activities. As a result, some young carers said that they prefer term time to holidays because at least during term time they get to see their school friends. One young carer talked of her boredom when out of school and dislike for school holidays:

- P21: Yeah, I like school. I don't like being off school, you know. I get really bored in the holidays and most of my friends would be doing loads of stuff, going on holidays. I'd rather be in school.
- Interviewer: So would you rather have shorter holidays?
- P21: Yeah, like one-day holidays and then go back to school. That would be great.

A 14-year-old caring for her mother and father explained just how caring impacted on her social life:

- P9: Well, like, if I was invited to one of their [friends'] houses, maybe I might have to stay at home because my brothers would be gone. Someone always has to stay with Mam and Dad's kind of not great in health either. Not very bad now, but he'd be able to mind Mam by himself for about an hour, two hours. But we wouldn't leave him here at night time with her because he'd need help.

Although this young carer would never go out when her mother did not have anyone else to mind her, at the same time, her older sister, living close by, could be relied on to ensure she was not called on to return home on the rare occasions she was out:

- P9: I'd never go. I would never go anywhere unless I knew there was someone going to stay with her. But Catherine wouldn't let anyone here go ringing me if I was out, like.

### ***Maturity***

Another reported impact of caring was greater maturity in the young carers. This took many forms. Almost every participant reported seeing themselves as more mature than their friends. Greater maturity often meant greater awareness of issues relating to illness and disability. In some cases, however, maturity meant the ability to empathise, to see other people's difficulties as well as one's own. This was the case with one 16-year-old helping to look after his 3 brothers with intellectual disabilities. He talked of his ability to see his own situation from someone else's perspective, in particular from the perspective of his brothers in need of care, and to see how comparatively privileged his position was:

- P19: Yes, I've got a different outlook on life, and how people think, and how different things can happen to people ... And you know, I have a better, I have an easier life than some people. So it's easier to see life in a range of different feelings and thoughts and stuff like that.

Some young carers seemed to feel resentment at the extra responsibilities and the expectation that they be more mature than their years. This appeared to be the case for a 15-year-old caring for her brother with autism:

- Interviewer: And would you say you had to become more grown-up or more mature?
- P5: Yes.
- Interviewer: In what ways would you notice that about yourself?
- P5: Well, I had to deal with an adult situation when I was 8 years old. So, I kind of picked it up from then.

Greater maturity could also mean an ever-present awareness of the seriousness of the situation and the responsibilities involved. One 14-year-old girl, caring for her brother with intellectual disabilities, referred to the possible negative consequences of not playing her part as a carer:

- Interviewer: OK, so would you reckon that, say, compared to your friends, you are more grown-up or more mature?
- P23: Not more mature, but maybe that I would have a bigger responsibility with my siblings. It's not just you have to mind them, or that you don't want to; it's that if you don't mind them, it can end up badly or something.

### Emotional impacts

The study also looked at the ways in which caring affects emotions. Besides exploring whether they were happy with their situation, the research team was also interested in the young carers' emotional and psychological development, and factors that might impact positively or negatively on this. The emotional impacts of caring on the young carer varied. Some reported that the person cared for was very happy and that they were happy to be able to help. This was the case with a 14-year-old carer helping with her brother who had intellectual disabilities:

- P23: Our life is actually pretty easy ... It's not like a chore or anything. It's just something that comes with my life, it's no extra thing.
- Interviewer: And it sounds like he's pretty easy to mind, is he? That he's kind of happy, as you said?
- P23: Yes, he's an extremely happy child and that makes it so much easier because if there is ever something wrong, you can tell straight away.

One source of worry and concern was what the future held for the person in need of care. A 16-year-old, caring for her brother with autism, found it difficult to come face to face with disabled adults:

- P22: There was a programme, to go down to a centre to help with grown people with disabilities, physical ones and mental. But I asked to be excused from that because I didn't want to see what he would be like in about 20 years or so. I just thought it might upset me.

A 16-year-old young carer was the primary carer for his mother who suffered from mental illness. He worried about the fact that his mother would not accept that she was unwell:

- Interviewer: So how did you feel about having to help out with your Mum? Did it worry you or were you glad to be able to help?
- P25: I was worried actually.
- Interviewer: In what ways were you worried about her?
- P25: Because sometimes when I tried to help her, she wouldn't listen and all that. She felt like she didn't need my help.
- Interviewer: So she'd find it difficult to accept that she needed ...?
- P25: Yeah.

The same young carer also frankly said that he felt close to his mother only when she was well:

- Interviewer: So would you say that you feel closer to your Mum because you had to care for her or less close to her?
- P25: Less close to her. I'd be scared to talk to her and all that because she'd start getting angry with me then.
- Interviewer: OK. Yeah.
- P25: When she was better, then I was close to her.

### Poverty

A further impact of caring on carers concerns poverty and socio-economic disadvantage. In a number of families where a parent had a disability, it seemed that disability does impact on the resources available in the family. A number of families in this situation were totally dependent on whatever income support they were entitled to receive from the State. This was the case for 2 sisters caring for their siblings and father, a teenage boy caring for his father after the death of his mother, and a young girl helping her mother with a sensory disability.

Poverty also impacts on the provision of care for siblings. Some young carers worried about the provision of care to siblings when they, the young carers, would be adults. They worried that, due to the absence of any alternative comprehensive form of support, their caring responsibilities would continue into adulthood.

### Impacts of intimate and/or general care

So far, the study has looked at the general impacts of caring on young carers. However, the tasks that a young carer performs may be highly significant concerning the impacts of caring. Therefore, in this section the impacts of performing intimate and/or general care tasks are explored.

Of the 26 carers in this study, 21 were performing intimate and/or general care tasks. Table 12 shows the positive and negative impacts reported by participants involved in such care. The reader should note, however, that not every one of the 21 gave positive and/or negative reports in every category. It is for this reason that, for example, there were only 11 reports of negative and/or positive experiences in the 'closeness' category. At the same time, respondents gave multiple responses and could record negative and positive experiences in any one category. Thus, there were 8 negative and 16 positive reports in the 'social' category.

**Table 12: Impact of care for young carers reporting intimate and/or general tasks (n = 21)**

Area of impact (multiple responses)	Negative reports	Positive reports
Social	8	16
Education	15	9
Physical	8	0
Emotional	16	10
Maturity	1	15
Closeness	3	8

While some of the participants (8) recorded negative 'social' impacts, twice as many (16) recorded positive 'social' impacts. In contrast, 15 reported some form of negative impact in 'education', while only 9 reported some positive impacts. Large numbers reported both negative and positive 'emotional' consequences of caring. A majority reported feeling more 'mature' than other people of their age. Similarly, while 8 reported feeling 'closer' to the cared-for person as a result of caring, only 3 reported any ambivalence on that matter. (As noted elsewhere, other respondents reported feeling no closer to the person cared for than their other relatives, or no closer than is the case between friends and their relatives.)

Some of the young carers who were providing intimate and/or general care did seem to be faring well despite their caring responsibilities – and perhaps to some extent because of those duties. One 16-year-old reported that although he sometimes felt stressed at school and although sometimes he had no time for his friends and his various interests, nonetheless he was happy to be able to make his brothers' lives easier. This young man (P19) was particularly outgoing and engaged in many activities: not only did he play for various GAA teams, he was also a musician and played every week at a nursing home on a voluntary basis. Yet another young carer (P17) in such a situation, by and large, had only positive things to say about the way his life was going. He was happy to 'divert' himself and care for his brother, and in any case had plenty of time to be with his friends.

In contrast to these two seemingly well-adjusted young carers, there were those who did not seem to have adjusted well to their caring role or those who were bearing burdens that may be too great at their age. Some of these carers have suffered back injuries as a result of their caring tasks. In many cases, school attendance was poor and in one case the carer had actually left school. There were those who were distracted in school and who worried about their relative in need of care. Some seemed to feel resentful at having to deal with an adult situation at such an early age. Many did not have anyone to talk to, as their parents could not or did not explain what was happening to their lives, and they did not get help from peers, teachers, youth organisations or healthcare professionals. Some felt that they never get a break from their caring, in particular if they share a room with the person in need or if the others in the home do not share the burden equitably.

## Impacts on primary young carers

So far, the impacts of caring on the carer have been examined and the impacts of performing various tasks. The focus now turns to the ways in which primary and secondary carers felt that they had been impacted.

There were 9 primary carers in the study. Again, the reader should note that not every primary carer reported positive and/or negative impacts in every category and also that respondents gave multiple responses and could record negative and positive experiences in any one category.

As Table 13 shows, of the 9 primary carers in the study, the majority (8) reported negative experiences in 'education', while only 2 reported positive impacts. More positive 'social' impacts were reported than negative ones, while more negative 'emotional' experiences were reported than positive ones. All participants, bar one, who addressed the question reported positive responses for 'maturity' and all bar one reported positive responses for 'closeness'.

**Table 13: Association between impacts and status as primary carer (n = 9)**

Area of impact (multiple responses)	Negative reports	Positive reports
Social	4	7
Education	8	2
Physical	4	0
Emotional	7	4
Maturity	0	6
Closeness	1	5

One of the primary carers in the study was a 17-year-old caring for his father after the death of his mother. He spoke of how one result of his mother's death, and his taking on much of her caring role, had been to bring him and his father closer:

**Interviewer:** And do you think the fact that you look after your Dad in the way that you do makes you closer to him?

**P2:** Much closer, yes. Before my Mam died, because she had him so much and because he was in and out of hospital, you know, it wasn't, like, I got on great with him, but there was always something, not missing, but since ...

**Interviewer:** Yes, probably just not that closely involved, I suppose?

**P2:** Exactly, and since this, now, just talking to him more even.

This primary carer did not say anything that would indicate he felt resentful of his caring responsibilities or alienated from his family or friends.

A 16-year-old girl, caring for her father with a mental illness and her 3 siblings with intellectual disabilities, saw benefits as a result of her caring role:

**Interviewer:** So how do you feel about having to do this? Are you glad to help out?

**P15:** Yeah, because you learn so much responsibility and everything for when you're older.

Her sister, also a carer, appeared similarly unperturbed by her caring responsibilities:

**Interviewer:** And how do you feel about doing it? About helping out?

**P16:** It's normal to me, like, to be honest. I don't take any notice any more.

Nonetheless, despite their positive feelings about their roles as carers, one of these sisters said that if there was a crisis in the household concerning her brothers or father, both sisters would leave school straight away to address the problem themselves – as was seen earlier, in

the comment ‘*School would be the last thing*’ (see p. 53). Both sisters reported that they had many friends who called to the house and even that those friends pitched in and helped with the housework. Neither sister indicated that they performed intimate caring tasks. However, both expressed a wish for more home help in particular, so as to lessen the burden of housework. In that way, they indicated that they were taking on too much to be able to cope. What is more, the impact of their caring responsibilities on their education could be severe, especially as they were entering the final years of secondary school.

### *Primary carers providing intimate and/or general care*

A further issue is the extent to which those performing intimate and/or general care tasks are also primary carers. Table 14 shows that all 9 of the primary carers in the study performed domestic tasks. However, 7 of the 9 did not report performing any intimate tasks, although 6 of the 9 did perform general care tasks.

A large number of the 17 secondary carers in the study were performing intimate care tasks, a higher proportion than among the primary carers. Also, a higher proportion of the secondary carers were providing general care. This would indicate that even though there was an adult in these homes not in receipt of care, these young carers were taking on tasks that many would consider age-inappropriate.

**Table 14: Association between tasks performed and status as primary or secondary carer (n = 26)**

<b>Caring task performed (multiple responses)</b>	<b>Primary carer (n = 9)</b>	<b>Secondary carer (n = 17)</b>
Domestic tasks	9	17
General care	6	13
Child care	0	15
Intimate care	2	12
Emotional care	2	5
Other	0	7

Eight of the young carers were both primary carers and also involved in intimate and/or general care. This would suggest that this group should be the focus of serious concerns about the negative impacts of caring on their present well-being and future development.

One such young carer was absent from school with back problems. She often felt bored when she was in school, reported having very few friends and said that she did not have enough time to herself. Yet another young carer in this situation reported hurting her back through lifting her mother. Although she was still in school, she would absent herself whenever her mother needed care and services were not there to cover that need. One other carer in this situation was very happy with her social life and did not voice any resentment at her caring role. However, she too prioritised care over everything else, in particular school. Finally, the youngest young carer in this situation, an 11-year-old boy, reported that he had enough outside help (in fact, that there were too many people helping, he said) and that he was free to run around and play with his friends. However, because he was an only child and because his mother was often absent receiving treatment, his situation pointed towards the issues of isolation and loneliness.

### **Impacts on secondary young carers**

While examining the impacts of caring on the 17 secondary carers in the study, the reader should again note that participants were able to make both positive and negative reports for each category, but also that not every participant made reports on each category.

As Table 15 shows, a significant number of secondary carers (12) reported negative experiences in the area of 'education', while only 7 reported positive impacts. There was a larger number of positive 'social' experiences (8) reported than negative ones (5). In a small, but significant number of cases (6), respondents referred to the negative 'physical' impacts of caring, including loss of sleep, being bitten and hit by a sibling, and back strain from lifting a parent. The majority (7) of those who responded to the question claimed they felt 'closer' to the person cared for; only 2 young carers gave ambivalent answers to this question, which were recorded as negative impacts.

**Table 15: Association between impacts and status as secondary carer (n = 17)**

Area of impact (multiple responses)	Negative reports	Positive reports
Social	5	8
Education	12	7
Physical	6	0
Emotional	8	9
Maturity	1	13
Closeness	2	7

Although many participants reported feeling closer to the person receiving care, for one secondary carer, a 16-year-old, because of her brother's autism she felt both closer in some respects and unable to get close in others:

P22: Well, I suppose it goes both ways. Because you feel closer, you know. You're helping more and he's more eager to ask for help than if he was normal. If he was normal, he'd probably be more independent, not dressing him and getting food for him and everything, brings you closer together ... Just a huge gap otherwise because there's no, can't communicate through speech and he thinks in a different way, so there's a bigger gap. So it goes both ways: you can be closer and further apart ... if that makes sense.

A 14-year-old, caring for her brother with autism, spoke about being more 'motherly' than her friends. She emphasized her maturity and empathy outside the home among her friends:

P23: Yes, I'm very motherly in that sense ... If anyone ever gets hurt or anything, I'm always kind of the one who knows what to do and I'm always the one who would look out for my friends if they were in trouble or anything.

## Care and gender

Gender has already emerged as an important variable in caring. This is the case, in part, because the majority of participants in the present study were female and also, as detailed in the literature review, the majority of carers in the Irish population across all ages are female (62%). However, in the 15-24 age category, the recorded number of male carers was 5,621 and the number of female carers was 6,665, and so male carers represent 46% of the caring population in this age category. Furthermore, the gender of the carer and the person cared for is also an important variable when considering if the care is or is not appropriate.

Table 16 shows the association between gender and caring tasks performed by the young carers in the study. Every male participant and every female participant in the study reported that they were engaged in domestic tasks. Just under half of male participants (3) and a large majority of female participants (13) reported providing some form of intimate care. A large proportion of both male and female carers were also providing general care and child care, although the numbers recorded providing emotional support were small. One significant difference between male and female carers was that, while 6 female carers reported providing 'other' kinds of care, this was the case with only one male young carer.



**Table 16: Association between gender and caring tasks performed (n = 26)**

Caring task performed (multiple responses)	Male (n = 7)	Female (n = 19)
Domestic tasks	7	19
General care	5	14
Child care	4	13
Intimate care	3	13
Emotional support	3	4
Other	1	6

Of the 7 male young carers, 4 were caring for a brother, 1 was caring for a father and 2 for their mothers (see Table 17). In the latter case, neither boy reported performing intimate care tasks for their mother. None of the 7 male young carers provided care of any kind to a sister or parent.

**Table 17: Association between caring tasks, gender of young carer (MALE) and person cared for (n = 7)**

Caring task performed by MALE young carers (multiple responses)	Mother cared for	Father cared for	Brother cared for	Sister cared for	Grand-parent cared for	Total people cared for
Domestic tasks	2	1	4	0	0	7
General care	2	0	3	0	0	5
Child care	0	0	4	0	0	4
Intimate care	0	0	3	0	0	3
Emotional support	1	0	2	0	0	3
Other	0	0	1	0	0	1

Of the 19 female young carers, 4 were caring for a mother, 3 for a father, 7 for a brother, 5 for a sister and 2 for a grandparent (see Table 18). Of the 13 female young carers providing intimate care, 4 were caring for a sister and 2 for a mother. Although none were providing intimate care to a father, nonetheless, 6 were providing intimate care to a brother. In contrast, as we have seen, none of the male young carers reporting to be providing intimate care did so for a sister or for a parent.

**Table 18: Association between caring tasks, gender of young carer (FEMALE) and person cared for (n = 19)**

Caring task performed by FEMALE young carers (multiple responses)	Mother cared for	Father cared for	Brother cared for	Sister cared for	Grand-parent cared for	Total people cared for
Domestic tasks	4	3	7	5	2	21
General care	3	2	5	4	2	16
Child care	0	0	8	5	0	13
Intimate care	2	0	6	4	1	13
Emotional support	1	0	2	2	0	5
Other	1	0	2	1	2	6

In some families, it was clear that the gender of the young person had a marked effect on the distribution of caring tasks. This was so for a 14-year-old who cared for her mother and her father. She stressed that her responsibilities as a carer were very different from the responsibilities of her brothers, even though her brothers were living at home and some were older than her:

- Interviewer: So a lot of that kind of falls to you?
- P9: Yeah, it would because the lads decide where they go first. Well, sometimes like, my sister does give out to them a lot, saying that I should get to go where I want, but I do get to go places most of the time.
- Interviewer: So do you think it's because you're a girl or because you're the youngest, or both?
- P9: Bit of both.

The same young carer explained how a specific task (helping her mother into bed) was designated:

- Interviewer: And does she need help getting in and out of bed?
- P9: Yeah. It depends on who is putting her to bed, but I'd do it mostly.
- Interviewer: Right.
- P9: Kind of depends, who has done the most all day and the person who has done the least has to put her to bed.
- Interviewer: Right.
- P9: I'd probably do it just to avoid the argument, like.

In other families, however, boys took on considerable caring responsibilities and often did so without expressing any reluctance. A male young carer, 16 years of age and caring for his 3 brothers with intellectual disabilities, said that caring was not so much a duty but that, as an older brother, he felt he should help to make their lives easier:

- P19: I just see it as a duty as their older brother, you know. But obviously sometimes I'm asked to help out with them and I'm grand with that. But, you know, I also personally feel that if I can make their life a bit easier for them, then I'm happy, do you know. So, I think it's not as much as a clear duty to me ... I just feel that I am their bigger brother so I should help, you know.

## Summary

- Of the 26 participating young carers, 20 were referred to the study by agency staff from the non-statutory sector and 6 were referred by the statutory sector.
- In total, 7 of the young carers were male and 19 were female; 10 were aged 5-11 and 16 were aged 12-17; the average age of participants was 13.
- Two of the young carers were non-Irish nationals. All 26 participants were fluent English speakers. The study did not have participants from the Irish Traveller community.
- Of the total sample, 15 of the young carers were caring exclusively for a sibling(s) and 7 were caring exclusively for a parent(s).
- All the young people caring exclusively for a mother or exclusively for a father lived in one-parent families (the exception was a young carer caring for both parents) and all those caring exclusively for a sibling(s) did so in two-parent families.
- There were 8 young carers living in households without any adult in paid work; these were all one-parent households, where the parent was in receipt of care from the young carer (the exception was a household where siblings were also in receipt of care). A total of 7 young carers lived in households that contained 2 adults in paid work; in all cases save one, the young carers were caring for siblings (the exception was a household where a grandmother was cared for by 2 young sisters).
- 11 of the participating young carers lived in rural areas and 15 lived in urban areas.
- The majority of participants (19) had begun caring below the age of 9 years.
- Of the 28 people in receipt of care from the participating young carers, there were instances of behavioural or learning difficulties (13); intellectual and physical disabilities (6); physical illness (5); mental illness (3); and one case of sensory impairment.
- 9 of the participants were primary carers (i.e. the predominant carer in the household) and 17 were secondary carers (i.e. they helped the primary carer to provide care).

- Of the supports that young carers reported that they were receiving, the most frequently mentioned was home help. This was followed by peer support, income, treatment and respite, support from teachers, advice, transport and money for renovations. Young carers also wanted to receive more of these supports, in particular home help, respite, peer support and support from teachers.
- Where home help was not sufficient, young carers felt over-burdened. Many also felt that they did not have enough information about the medical condition in question or about future care needs.
- The young carers performed many different kinds of tasks. All reported performing domestic tasks; 19 reported performing general care; 17 performed child care; 16 provided intimate care; 7 provided emotional support, and 7 provided 'other' kinds of support.
- Intimate care tasks included bathing, toileting and dressing. Both male and female carers provided intimate care; in some cases, girls provided intimate care to a parent and to brothers.
- The negative impacts of caring on the young carers included physical symptoms (such as back strain caused by lifting an adult) and in some cases their education was impacted negatively by distraction and absences from school. While most gave positive reports of their social life, caring also restricted their time to socialise with peers. Nearly all reported feeling more mature than their peers, although some did not welcome the extra responsibilities of caring. In some cases, the young carers worried about the future care needs of the person being cared for.
- Primary carers also reported both positive and negative impacts in the various areas mentioned above, although in some cases education in particular was negatively affected.
- Of the 21 young carers performing intimate and/or general care, some were affected in positive ways in respect of education, social life and emotions, while others experienced absences from school, inability to meet friends and excessive worry and anxiety.
- Although the proportion of male young carers who were primary carers and performed intimate and/or general tasks was similar to the proportion among female young carers, nonetheless, in some households care tasks were taken up by female carers even when other male siblings were available and able to help.

# **5 FINDINGS FROM AGENCY STAFF INTERVIEWS**

**NOTE:** All names used in this chapter are pseudonyms. Each participating agency staff member was given an identification number and letter, ranging from PA1 to PA30. Quotes from participants are given throughout; they have been subject to minimal editing in order to retain the tenor of the comments made.

## Sample profile

A sample of 30 agency staff was recruited for the study and empirical work conducted with them in the form of semi-structured telephone interviews, each lasting approximately 30 minutes (*see Appendix 7*). As Table 19 shows, 13 participants came from the statutory sector (all bar one of this group were HSE employees) and 17 from the non-statutory sector. Among the statutory employees, 7 had managerial functions and 6 had front-line roles. Managerial roles included departmental directors, planning specialists and researchers. The front-line staff were working in the areas of disability, social work, community work, public health nursing, family welfare conference coordination and neighbourhood youth work.

In the non-statutory sector, the sample was made up of 11 managers and 6 front-line staff. At managerial level, participants worked as CEOs, executive directors and centre managers, but also the category included researchers, policy analysts and advocacy officers. The front-line staff included those working in the areas of family liaison and advocacy, social work and community work, and the provision of assisted living services.

**Table 19: No. of agency staff interviewed (n = 30)**

Statutory sector		Non-statutory sector	
13		17	
Managerial	Front-line	Managerial	Front-line
7	6	11	6

## Agency role

The role or remit of agency staff varied within the statutory and non-statutory sectors (*see Table 20*). Some of the participants in the sample had more than one role and, therefore, there are more roles recorded than participants. The sample included those who worked in research, planning, support and advocacy, provision of information, community work, various forms of therapy, youth work and social work.

**Table 20: Role of agency staff (n = 30)**

Role of agency staff (multiple responses)	No. of agency staff
Research	5
Planning	19
Support/Advocacy	11
Information	12
Community work	3
Therapy	10
Youth work	5
Social work	5

## Professional experience of working with and/or for young carers

Participants were asked what experience they had working with and/or for young carers. None of the participants reported that working with young carers was the primary objective of their professional role. In general, none of the participants had contact with young carers on anything but an 'ad hoc basis' (PA25). They would only ever 'stumble across' young carers (PA26). As a result, those who did have professional experience of young carers had either very little experience or only experience in a small number of cases. Staff from carers' organisations in the non-statutory sector reported that they were involved in awareness-raising campaigns concerning young carers, including an annual national 'Young Carer of the Year' award. Although they hoped to record young carers on their databases in the future (PA16), as yet they did not have the resources to 'draw in young carers' using their adult carers databases (PA5). The research team was also informed that carer departments in the HSE had 'no direct remit for young carers' (PA10). One interesting finding concerns those who reported having very little or no experience of young carers: of this group, 3 worked in the areas of disability and care in both statutory and non-statutory organisations.

When considering the lack of any ongoing, structured professional experience of working with and/or for young carers, it should be borne in mind that in Ireland there are no services designed specifically for young carers. There is therefore little reason to assume that the low levels of experience reported here by agency staff was just a peculiarity of the sample. At the same time, many of the agency staff were providing services to the families of young carers and some were providing services to the young carers themselves – although they did not call or recognise them as such – either as siblings of those with a care need or as children with their own needs. However, none were providing services specifically designed for young carers, although some wished to do so in the future.

It is for these reasons that the majority of the participating agency staff did have considerable awareness of young carers and also were keen to emphasize the significance of young people caring as an issue for service provision and policy.

## Own personal experience of young carers

The research team did not ask agency staff about their own personal experiences of young carers, as opposed to their professional experience. For example, participants were not asked if they themselves had been a young carer or whether they had relatives in such a role. Nonetheless, information about this issue emerged from some of the interviews. Agency staff in areas of community development, neighbourhood youth, counselling, care and social work all reported that at one stage in their own youth, they had performed caring roles within their families. Caring as a young person may give one a certain level of maturity and compassion, more so than their non-caring peers, and this may be one important factor explaining why someone enters a caring profession. However, it was suggested by one participant that although many young carers take to caring as a profession, in some cases this may happen because the experience of being a carer has narrowed what the person perceives to be his or her opportunities in life (PA13). This can be linked to the concern found in the literature that caring, in some instances, can have significant negative consequences for the education, social life and development of the young carer.

Some of the participants also had relatives who were, or are, young carers. This was the case in two instances. One of these participants was very much aware of the potential negative impacts of caring on the carer. Even though the young carer in question was shielded from intimate care tasks in this household, nonetheless, this agency worker (PA24) highlighted how, generally speaking, young carers are in danger of getting less attention in the family and also they may be adversely affected by the stigma that can surround disability and illness.

## Definition of ‘young carers’

When agency staff were asked to define ‘young carers’, it became apparent that there were two radically different definitions of the term in use. The responses can be divided into two categories: (1) 14 agency staff believed that caring refers only to inappropriate care; and (2) 16 agency staff believed that there is a continuum of care and not all caring is inappropriate for children and young people (*see below*).

### Caring by children and young people is inappropriate care

Of the sample of 30 agency staff, 14 used the term ‘young carers’ to refer exclusively to those engaged in ‘inappropriate care’. Some of this group (4) believed that young people caring is by definition inappropriate, i.e. young people should not and need not be in a caring role, services can ensure this does not happen, and therefore it is incumbent on service providers to ensure young people are not in this situation. For this group, young people caring always fell below the threshold of acceptable family life and, therefore, it always registered as a significant need or a potential risk.

A further group of 5 (within the 14 agency staff who considered such caring inappropriate) began with a high threshold of concern – child protection. For this group, to say that a young person was caring was to say that the situation raised child protection concerns, i.e. a situation only merited being referred to as one of ‘caring’ if, and only if, it raised child protection concerns. These agency staff were of the opinion that service providers and policy-makers should focus on those at greatest risk and thus the term ‘young carer’, in their minds, referred to one subcategory within a larger category of children and young people at risk.

Finally, the remainder of the group (5) felt that while such caring was inappropriate, nonetheless, it should be recognised and supported. For this group, young people were affected in negative ways by their caring role. Some emphasized that caring by young people did not, in all cases, raise child protection concerns; others observed that young people caring was an unfortunate, but necessary feature of any family with a disability or illness; others felt that some of the negative impacts of caring could be lessened by the provision of specific services; and, finally, others noted that caring led to positive results for the young carers, as well as some negative impacts.

### Not all caring by children and young people is inappropriate

Of the 30 participating agency staff, 16 indicated that caring by children and young people need not be inappropriate. Some participants (10) stated that there is a continuum of caring. One argued that caring is unavoidable in a household where there is a medical condition, illness or disability. It was also observed that some of the tasks and some of the levels of responsibility can, if they are mediated correctly, have positive impacts. Nonetheless, the responsibilities of the young carer can and should be eased or lessened by the provision of various services. Moreover, in some cases, caring is problematic and raises child protection concerns, but it is important to distinguish caring from ‘risk’ and ‘vulnerability’, not only so that genuine cases of risk can be identified and responded to, but also so that unproblematic caring can be supported, recognised and, where appropriate and possible, eased or lessened. Two participants noted that it does make sense to say that everyone in a family with a disability, illness or other condition ‘cares’ in some sense. Nonetheless, if we think of caring as a continuum, then critical distinctions regarding the nature of care, its impacts and the supports needed can be made, and therefore it is possible to distinguish caring that is unproblematic from caring that does raise concerns.

Some agency staff (6) expressed reluctance to use the term ‘carer’ in many circumstances where this study has used the term. A special needs counsellor (PA1) argued that the term ‘sibling’ should be used to refer to young people that provide ‘some help’ in the home, while the term ‘carer’ should be reserved for those who have a designated caring role and perform a certain



number of hours of caring work per week, as, for example, when a parent(s) is absent. These agency staff wanted to make a clear distinction between those with a recognisable caring role and those who live with a person in need of care, but who are not themselves providing care. In contrast, as a social policy officer (PA12) argued, it is important to distinguish those who are 'just caring' from those who are caring and also 'vulnerable' – the distinction being between caring as a 'valuable role' and the vulnerable situation of, for example, a young carer in a violent household.

## Minors and young adults

There was further disagreement over the term 'young carers' among agency staff. Some believed that the term should refer to young adults as well as minors. They noted that many young adults continue to provide care for a family member whether they live in the family home or not, and that many of the issues that arise when minors are the carers also arise in these cases, in particular whether the care is age-appropriate and developmentally appropriate. In contrast, other agency staff noted that the status of being a minor has significant consequences for the young carer, in particular concerning the supports they can receive, how caring will impact on their lives and how they can be identified.

## Identification of young carers

As discussed in Chapter 3 (*see 'Recruitment of young carers'*), because young carers are a 'hard to reach' or 'invisible' population, the identification of young carers is both a difficult and also a deeply significant task. Although in this study some referrals were generated from agency staff who did not themselves take part in interviews, many of those who participated in agency staff interviews were also involved in the research team's recruitment of young carers. However, only 7 of the agency staff who participated in interviews were able to identify young carers who subsequently took part in the study (*see Table 21*). This group included those working in the areas of counselling and social work in the HSE and in the areas of community development, care, disability and autism in the non-statutory sector.

As Table 21 shows, many of those (7) who were willing to take part in agency interviews and took the time to search for referrals were, however, unable to produce those referrals. This group included those involved in youth work, care, neighbourhood youth and community work in the non-statutory sector, along with statutory sector personnel working in the areas of counselling, family support and care. Finally, 7 others simply felt that they would be unable to contact any young carers. These particular agency staff worked in the areas of care, social work, disability and children's services.

**Table 21: Referral of young carers by agency staff to this study (n = 30)**

Referrals	No. of agency staff
Were able to generate referrals for the study	7
Tried and failed to generate referrals	7
Felt unable to identify young carers	7
Not applicable	9

Many of those who took part in the study, 9 in total, played no part in identifying young carers (*see 'not applicable' category in Table 21*). Two researchers involved in the study were not in a position to identify young carers or make referrals because of the nature of their roles. A very small number simply had not been asked to identify young carers because the research team approached them at a point in the study when recruitment had ended. Still others had been asked to identify young carers, but no feedback was received as to whether any effort had been made to do so.

## Recommendations for identification of young carers

It was widely agreed among the participating agency staff that the identification of young carers is very problematic and that little is being done to try to establish and implement mechanisms to identify young carers. Comments were made such as: the issue is ‘under the radar’ for service providers (PA21) and it is ‘a forgotten issue’ (PA24). A family liaison officer working with families dealing with disability observed that they do not contact young carers nor do they even use the term ‘young carer’ (PA14). According to one carer development officer in the HSE, there is no active campaign to identify young carers or raise awareness about them, other than the Carers Association’s ‘Young Carer of the Year’ award (PA10). Indeed, one community worker observed that the only mechanisms to identify young carers were the latter award and the present study (PA9).

However, there were also concerns expressed about any attempts to identify young carers as things stand. One social worker believed that raising people’s awareness of the issue was problematic when no services were available specifically for young carers (PA4). First, a service should be established specifically for young carers and only then should a campaign of awareness-raising be embarked upon (PA25). However, it was also argued that, because young carers will often be deeply involved in household tasks, they may not be easily identifiable as ‘needy’; what is more, they may have less time than most young people to engage with service providers (PA2).

Potentially, young carers can be identified by contacting families where it is known that one family member has a significant care need and/or is in receipt of informal care from an adult in the home. If there are young people in the household, it is reasonable to assume that those young people may be involved in the provision of care (PA16). As a policy officer from a carers’ organisation observed, since there is no formal mechanism available to identify young carers, it can only be done at present informally through contact with the family in question (PA12). Alternatively, it was recommended that public health nurses would be able to identify such families (PA21). However, as one community worker believed, many parents will deny that their children are young carers (PA9). A special needs counsellor was able to identify many young carers because the service in question was in part domiciliary. Even so, it was felt that it would be unwise to try to raise the issue of the presence of young carers in some families because the parents in question would not accept that their children were young carers (PA1).

Other mechanisms were recommended for the identification of young carers. If an abusive situation is discovered, child protection procedures will uncover the presence of young carers, according to a neighbourhood youth worker (PA8). In addition, it was suggested that the Youth Diversion Programmes run by An Garda Síochána would highlight young carers (PA12). Further, where there is a problem with parental alcohol and drug addiction, social work services or family support services will be able to identify the responsibilities taken on by the young members of the family. School is another place where young carers may come to light: home liaison officers from schools should be able to uncover this information, according to one school counsellor (PA11), and they should be identified in the Early School Leaving Programmes (PA12).

However, at present, information is not being collected on young carers through these various mechanisms in any structured way, according to one policy officer in a non-statutory body, who observed that when a child protection notification is completed, there is no place to record the presence of young carers in the home (PA23). Nonetheless, one participant (PA5) suggested that non-statutory agencies could record the presence of young carers by, for example, using the databases of adult carers in the carers’ organisations to infer where young carers may also be present; however, it was felt that resources were not available to do this at present.

Although the relationships that have been established between agencies and families provide various possible ways in which to gather information on young carers, nonetheless, data can be collected through other means as well. The OMCYA has already suggested that more data can be collected on young carers through the Census and this was also proposed by a children’s rights expert (PA6); at present, the Census only records information about young carers over the age of

15 (PA12). Another option is to provide ways in which young carers can come forward to offer information about themselves. Traditional methods, such as free phone numbers and support groups, will not work for this younger generation, according to one participant (PA3). Instead, use could be made of websites and on-line social networking sites. The imaginative use of the Internet in the UK by 'young carer projects' was noted by many as an example from which we can learn in the Irish context. Such on-line sites might also enable researchers to carry out on-line surveys; since these would be anonymous, it might encourage the participation of more young carers from a greater diversity of backgrounds (PA12).

Because the issue of young people providing care is itself sensitive, this can be an obstacle to these young people participating in research. The present study found in many cases that either the parents or the young carers, or both, were unwilling to give consent to participate in the research. On the one hand, some parents were not approached by the study's agency staff 'gatekeepers' since they felt that those parents did not recognise that their children were young carers (PA1). On the other hand, it was argued by some that we must rely on mediators, or gatekeepers, because young people will not come forward and identify themselves as young carers (PA3). Vulnerable carers are even less likely to take part in research, it was argued; it was believed that parents of vulnerable young carers would be afraid that identifying their children as young carers could lead to child protection interventions in the family (PA12). The research team did find it difficult to attract such vulnerable young carers to the study and included only one family where the children had been taken into care. Furthermore, the research team were warned to expect to come across cultural differences concerning the approach to care and gender roles, in particular among Irish Travellers and new ethnic communities (PA2). However, the study was unable to include participants from these groups, despite gatekeepers making initial contact with three Irish Traveller families.

## Interviewing young carers

Agency staff were also asked about the issues likely to arise when interviewing young carers. It was argued that the young carer may find the interview itself a very emotional situation (PA10). This may be the case for a number of reasons. The young people may have 'adjustment issues' in dealing with an injury to a sibling or a parent (PA14). They may have a 'sense of loss' if their parent(s) is now changed as a result of injury or illness (PA15) and we can expect that the young carers will be aware of changes in their parents' relationship, should they have occurred, as a result of a disability or illness (PA25). The interview itself might raise worries and fears for the first time, in particular about the future development of an illness or about the future care needs of a relative (PA17). What is more, prior to being contacted by the research team, the young carer may have been unaware that he or she is a carer, never mind a primary carer (PA22). The interview should take place in an environment in which the young carer feels safe, it was argued (PA5). As carers may become upset talking about their situation, this might be a counselling situation (PA16) and the researchers should have some access to a counselling service if this is ever needed by the young carer. However, it was also recognised that the willingness to refer children and young people on to such services may make parents fearful of how the caring situation is perceived and the possibility that it will lead to child protection interventions (PA4). The research team were advised to send participants a 'Thank You' card (PA5); this was done and also included with it were details on the Carers Association, its regional offices and Freephone information and helpline.

Some agency staff warned that face-to-face interviews with young carers may be problematic in relation to the validity of the information generated. Some believed that children and young people can be reticent (PA10). The research team were advised that 'some young ones feel they should give the answer you want' rather than the correct or accurate answer (PA24). Others pointed out that the participants might not tell the truth (PA16) and in any case the interview might be influenced by the fact that the young carer may be under stress as well (PA19). At the same time, however, it was believed that children and young people are honest and by and large like to be heard (PA13, PA22) and they should be made feel that they are helping the researchers to learn something (PA6).

Some agency staff felt that the research team should reassure the young carer that their interview will not lead to any negative consequences for their family, and in particular that no one will intervene in the family as a result (PA6). This was felt to be necessary to ensure the autonomy of the participant, i.e. to ensure the young person felt free to speak frankly and honestly. However, as researchers working with children and young people, the team could make no such commitment. In fact, the research team had to ensure that another adult was present in the same room or in close proximity during the interview (PA5). What is more, the *Children First* national guidelines entail that the research team could not guarantee complete confidentiality to someone under the age of 18, as some agency staff pointed out as well (PA7, PA12). Finally, it was advised that, should specific needs be made apparent in the interview, the research team should ensure the young carer is linked in with a service provider (PA11, PA15).

### Some learning points concerning interviews with young carers

- The interview may be an emotional situation for the young carer for a number of reasons, including the young person's adjustment issues and/or sense of loss.
- The interview itself may cause worries or concerns for the young carer for the first time.
- Researchers should be ready to refer children to service providers should the interview be upsetting for the young carer.
- The validity of findings from interviews with children is an issue.
- The *Children First* national guidelines require that any guarantee of confidentiality is limited by the researchers' obligations to pass on any disclosure of abuse or neglect.

## Professional knowledge of young carers

Interviews also brought to light the levels of awareness among agency staff in regard to young carers. One professional working with people with disabilities noted:

PA15: It's not my experience that there are significant numbers of young carers out there. The people we would deal with in the caring capacity are often a partner, a parent, an older parent, who are looking after their husband, their brother, their son or daughter ... [I have] never come across a situation where there was a child involved in personal care.

A carer specialist in the HSE felt that there were no young carers who were the 'primary' carer in the household. This participant felt that the main concern of parents in families with a disability or illness was about being unable to spend enough time with their well children. They were not concerned that their well children were providing too much direct care (PA29).

A carer specialist in the non-statutory sector also did not believe it likely that primary school children were 'doing a lot' of caring:

PA16: I think primary school is too young. You're not really going to get – now there may be cases out there – but I can't imagine that there are cases of such a young child being left to care for somebody within the family ... Some of the cases are, I suppose, very very difficult, that they are doing a lot of the caring. But it's more so in the secondary school level that they would be.

Another participant, working closely with families where there is a disability, also had no first-hand experience of young carers providing 'direct care' and/or 'inappropriate care':

Interviewer: Have you seen or are you aware of situations where young people are providing care that you feel may not be appropriate to their age?

PA14: We wouldn't really come across young carers providing direct care. That's not to say they're not – just it's not something we've come across.

Interviewer: Right, OK.

PA14: I think they're often exposed to things we would prefer they were not exposed to, in terms of the difficulties they're having to live with. But certainly not in terms of actual responsibilities, no.

One staff interviewee believed there was no 'inappropriate care' (taken to include intimate care) being provided by any young person that they were aware of (PA4). Finally, another participant believed that, in general, teachers would know about a young person's caring role and otherwise this would be a 'horrible situation' for the young carer (PA12).

The interviews suggest low levels of awareness concerning young carers among professionals working in the areas of children and family. In some instances, professionals showed such gaps in knowledge even in regard to the young carers they referred to the study. Professionals have contact with young carers only on an 'ad hoc' basis and for that reason it is understandable if there are significant gaps in professional knowledge in this area. This would suggest that not only is there a need for better service provision, but also for awareness-raising and training among professionals. Indeed, much of this would be accepted by the agency staff who participated in this study, given that they believed the issue was not a priority area for service providers or policy-makers: it was, according to one participant, 'off the radar'.

## Supports for young carers

Agency staff were asked about the types of support and assistance their organisation *did* provide to young carers and also what kinds of support *should* be provided to young carers, whether by their organisation or others. Table 22 records the answers given to the first of those two questions, i.e. what the participants said were the key objectives of their organisation in relation to supporting young carers. In many cases, more than one kind of aim or objective was mentioned (multiple responses).

**Table 22: Key objectives of agency staff (n = 30)**

Key objective (multiple responses)	No. of agency staff
Child protection	9
Support for young carer	15
Family support	7
Services to the person in need of care	8

Some of the agency staff (9) emphasized child protection issues and, therefore, in the main they provided services to young carers when it was felt that the young carer's home life raised child protection concerns. Other participants (7) drew attention to the idea of family support. When they supported the young carer, they did so as part of a package of services intended to support the whole family. Others (8) prioritised the assistance that could be provided to the individual with the care need, i.e. they responded to the situation of the young carer by providing services needed by the person in receipt of informal care within the home from the young carer. However, half the sample of agency staff interviewed (15) said that their objective was, at least in part, to respond to the needs of the young carer. It should be remembered, however, that none of the agency staff interviewed were in a position to provide services designed specifically for young carers since, crucially, neither the non-statutory carers' organisations nor the HSE carer departments have such services. The situations in which young carers were actually supported were: (1) as siblings of children with a care need or as children of a parent with a care need; (2) as participants in a youth service open to all children; (3) as part of a family benefiting from respite breaks; or (4) as a child in a family where there was an intervention made on the basis of child protection concerns.

Agency staff were also asked what supports *should* be provided to young carers, as well as what supports their organisation *did* provide. The answers to both questions are recorded below under the following headings:

- services to the individual with the care need;
- support for young carers as young carers;
- young carers as a child protection issue;
- young carers and family support.

### Services to the individual with the care need

**Normalisation, not isolation** – For some agency staff, the existence of young carers, caring informally for members of their families, is, in large part, a result of insufficient formal service provision in response to care needs. According to one youth worker, young people need not be young carers and better formal service provision to meet care needs should be the key objective:

PA2: I think what they need is normalisation, not isolation, you know. Not even reinforcement. They need to get away.

One participant stressed that children and young people should not be staying at home in a caring role just because the State's provision of services for the person with care needs is insufficient. However, this participant also acknowledged that some children and young people may freely choose to take on this caring role. It was crucial that services to meet care needs were such that children and young people had a choice as to whether they took on caring. It was argued that, taking the UN Convention on the Rights of the Child as a starting point, children should have:

PA6: ... [better] support and access to services, so children feel at least they have some sort of choice.

Of the young carers who took part in this study, home help was the support that most families did receive and it was also the most requested form of additional support. Agency staff believed the State could be doing more to provide home help, the purpose of which is:

PA22: ... to help them to live, you know, to be able to go out and to meet with their friends and socialise and do all of those things – that their whole life is not tied up with caring. I think that is a very very big gap from our service perspective.

If funding for services to address care needs is not sufficient, agency staff were of the opinion that there can be serious consequences for the person in need of care as well as for the rest of the family. One participant illustrated this point with the example of a household where assisted living supports were insufficient. This led to a greater caring role for the other adult in the household, as well as for the younger of two daughters. According to the participant, in this situation the primary carer (the mother) felt that the young carer (her daughter) was taking on too much in terms of intimate care responsibilities, but:

PA10: There was necessity there because there wasn't enough support initially being put in, even for the mother; and also it was an outstanding need, and the daughter could see that her mother needed the support.

**The pendulum has swung too far** – Other agency staff felt that, although in the past, many people who were placed in residential care should instead have been cared for in the community, 'the pendulum' has now swung too far in the other direction. According to one counsellor, families are now expected to care for their relatives without sufficient supports to ensure that they are not, as a result, experiencing severe negative impacts:

PA1: I don't think that brothers and sisters should have the solution to that, or should be looked on by the Government or the Health Services or voluntary bodies as being part of that solution ... They shouldn't be left with the burden of care that's going to impact on their children and their family life as well.



## Support for young carers as young carers

Although many agency staff believed that better services should be provided to the person in need (*see above*), a crucial part of the argument was that insufficient services had serious negative consequences for the informal carers because it increased their responsibilities, sometimes to the point where they could not cope. If informal carers are being impacted in negative ways by their caring responsibilities, this raises the question of what supports should be designed for, and targeted at, young carers themselves. It also forces us to address the fact that it is even difficult to identify young carers and understand their needs in the first place.

## Database and information

Some agency staff interviewed drew special attention to the fact that there is no national database of young carers in Ireland. With notable exceptions, service providers at present do not collect data on young carers. For example, it was pointed out by one specialist in alcohol addiction (PA23) that, in filling out a child protection notification, there is no place to record the presence of young carers in a household; as a result, information on the prevalence of young carers, and the tasks they perform, is either anecdotal or gathered in an ad hoc fashion. In addition, it was felt that this fell short of the State's mandate following on from the *National Children's Strategy* (Department of Health and Children, 2000) and *The Agenda for Children's Services* (OMC, 2007). In one HSE Local Health Office, the carer department had created a database for *adult* informal carers. Adult carers were asked to fill out a 'carers registration form' when they applied for services. However, the carer department in question had not created an equivalent database for young carers, nor does the information collected on the adult carers' database allow inferences to be drawn about the presence of young carers in the household. Indeed, it was felt that, if the carer department is contacted by an adult carer, the first objective is to establish a trusting relationship with that adult carer. If, instead, they are asked questions about the presence of young carers in their household and the tasks they perform, then 'at that initial stage they're [the parents] certainly going to feel that there is an inquiry, and trust would be an issue. So it wouldn't be appropriate' (PA29).

It has been suggested that a national database of young carers is needed so as to be able to estimate the numbers of young carers, the tasks they perform, the levels of responsibilities they take on and how this impacts on their lives. A related objective is to get a better understanding of the service needs of these children and young people. As another care specialist (PA10) emphasized, statutory and non-statutory agencies should collaborate to identify the supports needed and how they will be monitored and resourced. A 'national high profile committee' is required to establish a strategic approach to young carers so as to address the pressing questions arising from this issue: 'What supports are going to be put in place? How is it going to be monitored? How is it going to be resourced?'

## Supports currently provided to others and elsewhere

Agency staff interviewed also made more specific recommendations on the supports that young carers *should* receive. A care specialist (PA29) outlined the services that are available through the HSE to carers over the age of 18: these include carer training, counselling, respite care, home care and help applying for benefits. These supports were illustrated with the discussion of a university student who was a secondary carer: the carer department was in a position to provide her, as an adult, with counselling and with help applying for benefits and entitlements. This participant said that there was no legal obstacle to a person below the age of 18 being placed on a regional or national HSE database of young carers. The example illustrates how a secondary carer can nonetheless be recorded on the HSE database as a point of contact and as a part-time carer (if they are adults). If the same could be done for those carers who are below the age of 18, then they too can be included on a carers' database. Moreover, they too could be targeted by service providers so as to meet their needs as carers. One major obstacle preventing this from happening so far is the sensitive nature of this issue, in particular its sensitivity for the parents of the young carers.



As some participants pointed out, one highly successful initiative in the UK has been the establishment of ‘young carers projects’ at a local level across the country. These projects also provide a national database from which samples have been drawn so as to conduct surveys of young carers (*see also Chapter 2*). ‘Young carers projects’ could reasonably be said to offer emotional support to young carers since they show to the young carer that he or she is not alone in having these caring responsibilities. They can also organise events and outings, where young carers can meet each other and establish contacts with other young carers. They also provide information about medical conditions, how they may progress and the types of treatments and services available.

In the Irish context, some of the agency staff participants believed it would be wise to help establish ‘carer support groups’ at a local level. However, for this to happen:

PA3: We would need someone very forward thinking in the HSE, saying ‘This is the budget’ ... The supports now for family carers outside income protection come through the HSE Older Services and they’re not going to want to invest a couple of million in young carers. They would rightly say, ‘That’s young people’ [i.e. another department’s responsibility].

### *Awareness-raising and anonymity*

‘Young carers projects’ are just one possible method of raising awareness. In addition, awareness could be raised within schools, by supplying materials and information about care and carers. A particular concern here is to address the possible stigma around both the care needs and the caring role. A guidance counsellor (PA11) felt that when such awareness-raising projects are run in schools, the effect is to make both non-carers and carers more ‘sensitised’ to the caring role. While awareness-raising is recognised as vital, at the same time, agency staff also spoke of the need to consider anonymous forms of support. Young people might feel less inclined than adult carers to come forward and identify themselves as carers in face-to-face meetings, in particular if they feel intimidated by ‘official’ or ‘bureaucratic’ agencies. At the same time, it was observed that children and young people are more computer-literate now than ever before and have greater experience of on-line social networking. This might provide an opportunity to attract young carers to participate in young carer networks and forums. One suggestion was to provide on-line support and information and discussion for young carers.

### *Therapy, respite, income and inappropriate care*

One important form of support is therapy and counselling. In some situations, young carers may resent their caring responsibilities, they may feel neglected by their parents and also they may feel guilty for even having these feelings. A number of agency staff said that if caring is ‘inappropriate’, this may affect the young person’s emotional and psychological development. A special needs counsellor (PA1) spoke of referring siblings for ‘psychology support and that can be around behaviour problems or maybe around emotional issues as they get older’.

Sometimes the agency staff were able to organise trips away for young carers. However, the young carer’s ability to participate in social activities was made more difficult by their caring responsibilities. For that reason, one community worker stressed that any service provided to young carers must be done in a flexible way, even if this involves ‘breaking the rules’:

Interviewer: What types of support would you include for young people?

PA4: I do it, but under the radar. I would bring them away on activities as much as I can. One young girl – I’m breaking the rules – I would collect her at the door, to make sure she has the right stuff with her for the outing. Knowing what the problem is helps because you know what to watch out for.

Even if it is accepted that one objective of service providers should be to meet the needs of young carers, one way to do so is to better respond to the care need in question. Indeed, young carers themselves said that what they want is more home help, respite care, medical treatment and so on. Agency staff also agreed that young carers would ask for more home support:

PA29: And the reason for that is not just for the care recipient, but it gives them [young carers] a break. It stops the need for them being bound to the house so much. That really is the primary need.

The provision of respite is a potentially sensitive issue, however. One participant mentioned that, although it is important to provide respite, it is also important that the person in need of care is not, as a result, made to feel isolated from the rest of the family (PA1).

Adult carers are supported with income: they may be eligible for Carer's Allowance, Carer's Benefit and the Respite Care Grant. However, at present, the Carer's Allowance is only available to full-time carers above the age of 18, while Carer's Benefit is only available to those who have left the workforce to care for someone. The exception is the Respite Care Grant, which is available at the age of 16. A care specialist (PA17) argued that payments to young carers should be made because this would imply recognition of their valuable role.

Although there are strong arguments in favour of recognising the value of informal care, informal care will not be valuable in some circumstances. In many cases, the caring role of a young person could, and should, come to an end. It is argued that siblings and children and young people should not be expected to keep on their caring role after they reach adulthood, although of course some may wish to do so. Young carers and their families should be thinking of a 'Plan B', even if this involves residential care for the person with the care need (PA1). Therefore, one objective is to ensure that, to whatever extent possible, the young person's caring role does not become 'inappropriate'. According to a care specialist, service providers should try to 'prevent' this from happening and one thing that needs to be done is to provide better services, including those designed to ease the responsibilities of the primary (adult) carer:

PA29: I'd be very conscious that services need to be guided by prevention – protecting young people from falling into inappropriate caring – because sometimes it can become maybe the norm within a family and ... because they're not having contact with others, this becomes a family norm.

## Young carers as a child protection issue

### *Vulnerable carers*

In some cases, the situation for children and young people is such that they are deemed 'at risk' and it is judged that an intervention is needed so as to protect their interests. Although such experiences of extreme vulnerability are not well represented in this study's sample of young carers (for reasons already dealt with in Chapter 3 on 'Methodology'), some of the agency staff participating in interviews did have experience of such situations.

One reason why children and young people are made vulnerable is the alcohol or drug addiction of a parent or both parents. One social worker (PA7) explained that alcohol was a 'huge thing with mothers', although the children 'are masters of covering up'. One solution is to gain entry to the home with a Supervision Order, but this in turn leads to serious confrontations with the parents and worsens relations between the family and service providers. Another participant (PA20) worked with children and families placed in emergency accommodation. Once again, the young people were involved in care here as a result of the alcohol and drug addiction of their parents. A key objective was to break the intergenerational cycle of homelessness, but the service providers struggled both against a lack of resources and also the negative influence of some parents on their children.

### ***What is 'vulnerability'?***

Although most service providers agreed on the need for child protection policies where children and young people are at risk or in vulnerable situations, there was some disagreement as to what constitutes 'vulnerability' when discussing young carers. One community worker (PA9) felt that any situation of children and young people providing 'personal' care to a parent is a child protection issue. Another participant (PA3) believed that when it is 'young children' providing care, this is a 'child protection issue'. Yet another (PA4) thought that 'concern' arose only where a young person was providing 'intimate' care.

However, an alternative perspective focused less on the tasks performed and the ages of the young carers. Instead, as one carer specialist (PA12) observed, a distinction should be made between a carer and a 'vulnerable' carer, between caring as a valuable role and someone forced to care by a violent adult – what is important is the quality of the experiences and relationships. Another way to put this is to say that a child protection issue arises not because children and young people are caring, but only if this caring involves 'neglect' of the carer. According to one counsellor (PA26), children and young people can be said to be 'neglected' by comparing their situation with that of a 'normal' childhood in regard to education, social life and physical well-being.

### ***Children's rights***

If a key objective of services is to protect the interests of children and young people, it might follow that children and young people have 'rights' to such services. Some participants argued that it should be made easier for young people to access services on their own initiative. According to one disability worker, for this to be possible services would have to be streamlined and resources pooled:

PA15: [This would ensure] mainstream service provision that could deal with the need as and when it arises, as opposed to having 20 different numbers or agencies to contact.

In extreme cases, priority should be given to children's rights so as to act in the best interests of the child. As one child care manager (PA18) said, some children need to be taken into care due to the physical abuse they are subjected to at home: 'In terms of child protection, sometimes you just have to call a halt with some families.' Children should be prioritised in cases of physical abuse and neglect. However, it is also argued that the child's rights should be prioritised *in all cases*, in the sense that a child should not have to wait to receive a needed or wanted service until their parents or guardians decide to access that service for the child. The argument is that delays in meeting basic needs for children and young people damage the interests of a child and young person to a far greater extent than similar delays in respect of the needs of an adult, and this is the case because of the child's stage in the developmental process (PA23).

### ***Young carers and family support***

So far, agency staff have offered their views on various types of supports provided to individuals in need of care and to the informal carers, including young carers, as well as support that may entail protection of children and young people from neglect and abuse. Agency staff also discussed the support that can be provided to the whole family.

#### ***Some benefits of family support***

Some of the participating agency staff believed that supporting families is not incompatible with protecting children and young people – often the former can be the best way to attain the latter. Early intervention in the form of family support, for example, can prevent problems emerging in the future that lead to children and young people being taken into care. A disability worker (PA15) felt that in many cases the best way to respond to the needs of a child living in a home with disability is through family support, in particular a 'family support counselling session'; one beneficial outcome is that members of the family, including young carers, are given the chance of 'expressing ... that it [the care need] is a burden in many cases [even though] people don't like to use that word'.

One participant observed that the supports offered to families should be flexible:

PA26: They could flexibly work around allowing them to continue to supply the care. Like, home schooling and things could definitely be broadened out ...

The same participant felt that in rural areas in particular, a flexible approach may help combat social isolation:

PA26: There's a lot of families out there who have moved from different parts of the country and they're living in areas where they don't have a family network or any supports. And that's something else that's probably also going to give rise to more and more people, young people, in the caring role and being perhaps very isolated.

Again, the same participant went on to observe that such family support services can both support the young person as a carer within the family and protect him or her from inappropriate care:

PA26: I suppose the question is, should the same rules apply to young people taking a caring role as apply to young people who are in employment?

The issue being referred to here is that some young carers are working longer hours than they would be permitted by law to work in paid employment. As a result, they may be losing out on education and their social life as well. The argument is that a concern with family support allows service providers to help the whole family, while promoting the best interests of the child at the same time.

### ***Community support and integrated services***

Taking a family support approach can direct services to the whole family as well as to the individual with the care need. This approach also highlights the importance of the wider community and the way in which services should be integrated. According to one participant, 'community support' services can provide opportunities for young carers that otherwise they would not be able to gain access to because of their caring role at home:

PA14: ... programmes that kids could link in with, even after-school support, study support – those kinds of things. Their parents, perhaps, aren't there to support them in the same way.

It was argued that 'generally speaking, you would probably find that the reason that person is providing care ... is because the formal support services going in are not sufficient' (PA29). Thus, to respond to the needs of the young carer, the specific care need in question must be examined. This participant (PA29) went on to argue for an 'integrated' approach to such service provision. In 'a "whole systems" approach ... you're bringing together not just the needs of the care recipient, or the main family carer, but also the young person there ... in a supported way and providing support services together in consultation with the "whole family" approach'.

Although the need for more resources and the prioritisation of young carers' needs was voiced, none of the participants called for the establishment of a new statutory agency for young carers. Instead, as a carer specialist in the non-statutory sector argued, existing services can be both directed towards young carers as a policy objective and also coordinated in an integrated or holistic approach:

PA3: By that, I mean you need interventions through schools, youth services, community Gardaí, public health nurses and awareness – community awareness – through advertising.

### ***Suspicion and sensitivity***

Services can therefore be put in place that are designed to support the family. However, in situations where children and young people are if not vulnerable, then close to being so, it is thought that parents will often be suspicious of the objectives of service providers. This suspicion may, according to one social worker, prevent them receiving services that otherwise would support their family:

PA7: Even play therapy, like, they [some parents] don't see it as a developmentally appropriate way for children to get help. They're 'Oh my God, what are they [service providers] going to find out?'

Family support services are designed to help families through difficult situations, including disability, illness or other care needs. According to a disability worker, when the burdens of care are placed on the family to a greater extent, the pressure can result in stress and worry, and even 'psychiatric problems' for the parents, which in turn create more responsibilities for the young carers in the home. Supporting those families, by providing practical help on a day-to-day basis, can reduce those pressures significantly:

PA13: Practical support is somebody actually coming into the house and actually helping and being supportive and allowing Mam and Dad to go out and, you know, go for a walk or have a bath or whatever ... Practical support for people – and they will all say that.

According to one carer specialist in the HSE, services should be based on a 'whole family' approach because the person with the clinical need is not the only person involved. Nonetheless, a lack of sufficient funding prevents such an approach from being taken by this practitioner:

PA10: I can just tell you, a study that I've done here around support. [I asked] 'Do you get family, voluntary [or] statutory support?' And I had a hundred carers ... for that questionnaire and 70% of them ticked 'family' ... But we don't have either the time or don't have the system set up to look at the family as a whole unit. And even my service, because it's so stretched, is really only dealing with the primary or the main carers, and yet there are so many other people involved.

## Summary

- Interviews were conducted with 30 agency staff: 13 from the statutory sector and 17 from the non-statutory sector.
- None of the participants had contact with young carers on anything but an 'ad hoc' basis.
- 14 of the participants used the term 'young carer' to refer exclusively to inappropriate care and some of this group felt that it raised child protection issues.
- 16 of the participants believed that there is a continuum of care and that not all caring by children and young people was inappropriate.
- It was agreed that the identification of young carers would be difficult since the issue is 'under the radar'.
- While some believed that awareness about young carers should be raised, others felt that this should not be done until a service was available to meet their needs.
- Agency staff providing domiciliary services were in some cases able to identify young carers for the present study, but also in some cases would not do so if it was felt the families in question would not accept their children were acting as young carers.
- Young carers, it was suggested, could be identified by home liaison officers in schools.
- It was noted that, at present, professionals working in statutory agencies do not record data on young carers when delivering a service to a family.
- Non-conventional methods to identify young carers were also recommended, in particular the use of on-line social networking.
- Agency staff believed that interviewing young carers may be a sensitive situation and may lead to the need for counselling support for them.
- It was also suggested that, in interviewing young carers, caution needs to be taken since they may tell the interviewer what they assume the interviewer wants to hear.
- While the young carer should feel free to speak frankly in the interview, an adult must be either present in the room or in close proximity, and the *Children First* national guidelines entail that the young carer cannot be guaranteed complete confidentiality if a situation of abuse or neglect is revealed.

- Gaps in agency staff's knowledge of young carers were evident; this was the case even among those able to refer young carers to the study.
- In some cases, agency staff were unaware of the prevalence of young carers, their performance of intimate care tasks, the age at which they began caring or the 'primary carer' status of some of them.
- 15 of the participants saw it as their objective to provide supports to young carers when possible; 9 gave priority to protecting children from neglect and abuse; 8 were providing services to the person in need of care; and 7 were providing family support.
- Some argued that services to the person in need of care should remove the need for the child and young person to provide any care at all. Others, however, acknowledged that such services may only lessen the need for informal care.
- Services currently provided by the HSE to adult informal carers are not being made available to young carers, nor are young carers being placed on informal carers' databases.
- It was suggested that the equivalent of the 'young carer projects' in the UK should be established in Ireland.
- It was argued that a budget for young carers should be identified within the statutory sector.
- It was suggested that an awareness-raising project should be pursued through schools, in particular so as to address any perceived stigma around caring and/or the care need.
- It was stated that therapeutic services may be needed if a young carer is developing behavioural problems.
- It was noted that home help and respite are crucial supports for the informal carer.
- According to participants, young carers should not feel obliged to care for a sibling once they themselves become an adult.
- Vulnerable young carers have been discovered where caring is required because of the alcohol or drug addiction of a parent(s).
- Some agency staff believed that the provision of intimate care was a child protection issue.
- A rights-based approach was defended on the basis of the developmental needs of children and young people, and the relative urgency of meeting those needs.
- A 'whole family' approach was proposed, which seeks to support all members of the family rather than just the individual in need of care.
- Family support as an early intervention can prevent child protection issues arising later, it was claimed.
- A family support approach also requires an integration of services for the family.
- None of the participants called for the establishment of a new agency or service to support young carers.

# 6 DISCUSSION



This study has shown the reality of caring by children and young people aged 5-17 in the Irish population. Irish census data provide some information on carers in the 15-17 age category, but the interviews conducted with young carers in this study bring into focus, and give some meaning to, the lived experiences of young carers in Ireland today. Although there are many different types of caring in a variety of situations, nonetheless, the caring role taken on by children and young people is a very real phenomenon. Some of the children and young people in the study are primary carers, others are helping to provide care. Caring begins at a very young age for some and in many cases it includes intimate care and general care. Although there are many positive impacts of caring, and although it is not the case that all or even most caring is 'inappropriate', the negative impacts overall are serious and require a concerted response in terms of policy, legislation and service provision.

Uncovering the reality of caring is all the more important given that young carers are to a great extent 'invisible'. This is the case, in part, because young carers and their families are unwilling to use the term 'young carers' and to identify themselves as such. They are also 'invisible' because there are no organisations with the objective of representing their interests or providing services to them. Furthermore, many of the agency staff who took part in interviews disputed the reality of young carers as it has been uncovered in this research. It may be the case that in many circumstances professionals are wary of defining children and young people as carers because they fear what implications there may be in terms of child protection interventions in the family. A crucial issue, therefore, is whether and how to raise awareness about young carers, while at the same time not exaggerating the negative impacts of care and not turning young carers into a so-called 'welfare category' and 'pathologising' those with care needs (Olsen, 1996).

## Defining young carers

How should 'young carers' be defined? As discussed in Chapter 3, for Thomas *et al* (2003), a young carer is a child or 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*'. Gray *et al* (2008) rightly point out that young carers may '*provide, or help to provide, care and support*' and they take on '*a level of responsibility usually associated with an adult*'. However, in line with Frank (2002), the working definition adopted for the purpose of this study covers a continuum of caring. As Frank states, '*It is important to differentiate between a "normal" level of "caring" within a family and a level of inappropriate physical or emotional caring that affects a child's own personal, social and educational development*'. Thus, the working definition adopted for this study is:

A young carer is a child or young person under 18 years whose life is affected in a significant way by the need to provide care for a family or household member who has an illness, disability, addiction or other care requirement. This may include a child or young person who provides direct personal care or who takes on a supportive role for the main carer. A young carer may carry out domestic tasks or may provide general, intimate or emotional care. These needs may arise on a regular or on an occasional basis. There is therefore a continuum of caring and as a result the service requirements of young carers will vary. It is important to differentiate between a level of caring that has largely positive consequences and a level of physical or emotional caring that impairs the child's health, development or welfare.

As the literature review in Chapter 2 showed, however, some have suggested that the term 'young carers' is itself problematic and should not be used since it carries negative connotations for children and young people, parents and professionals (Olsen, 1996 and 2000). Also among the agency staff interviewed for this research, some feared that the term 'young carer' may stigmatise children and young people.

It is the case that there is a symbolic dimension to reality (Habermas, 1987). The categories used to refer to phenomena in the social world are themselves constructed through social processes and, therefore, the concepts we use can be heavily influenced by inequality, power and prejudice.

In some cases, such as the labels used in the past to refer to the intellectually and physically disabled, the social categories we use imply a stigma (Goffman, 1963). However, this need not be the case with the term ‘young carers’. The findings from the interviews with young carers in this study provide very good reason to accept the reality of the phenomenon of children and young people caring. That in itself is reason enough to use a label to refer to that experience. It is a separate issue, then, to ensure that the term ‘young carers’ will not be stigmatising. This conclusion is supported by the findings, for although the young carers were aware of the negative impacts of caring, many saw their caring role in a largely positive light: they were happy to help a family member and felt closer to the person as a result – summed up by one 16-year-old, caring for his 3 brothers with intellectual disabilities: *‘If I can make their life a bit easier for them, then I’m happy’* (this quote was chosen as the title for this report).

This study has defined ‘young carers’ broadly so as to include primary and secondary carers, and those who do and do not provide intimate and/or general care. This allows reference to the broad continuum of caring actually uncovered in interviews with the young carers. The argument for doing so is that the lives of all these children and young people were affected in significant ways by the care needs of others. It also follows that, although some caring by children and young people is inappropriate and involves ‘over-functioning’, this is not so in all cases. Moreover, if the term ‘young carers’ carries negative connotations, in some circumstances this is the result of a lack of awareness. Raising awareness is therefore necessary if the term ‘young carers’ is to refer to the reality of young people caring and not instead to operate as a mere stigma.

The findings of the study provide in-depth insight into the kinds of tasks performed by young carers in Ireland and the levels of responsibility they assume. Children and young people reported that they were providing domestic care, intimate care (in some case across gender lines and from child to parent), general care, emotional support, child care and other kinds of care. Although most of the young carers in the study were secondary carers, 9 from a sample of 26 were primary carers in their households. The vast majority of participants began caring before they had reached the age of 9. These findings are similar to those in the UK (Bearden and Decker, 2004). The reality, therefore, is that children and young people in Ireland are taking on significant caring responsibilities. As this is the case, the interests of young carers are also affected in important ways. Whether or not the interests of young carers will be given the consideration they merit will to a significant extent depend on the responses of relevant statutory and non-statutory organisations.

Some agency staff were sceptical of claims that young carers were performing intimate care tasks, or caring from below the age of 12 or acting as a primary carer. This study found that in some cases those who were sceptical were simply unaware of the nature and range of tasks being performed by young carers; in some of these cases, the young carers in question actually were known to the agency staff. This finding should not come as a great surprise since it is acknowledged that young carers are ‘invisible’ and also that none of the agency staff interviewed had a professional responsibility for young carers. Nonetheless, it also suggests that the knowledge of agency staff, and their training, in the area of young carers should be addressed.

Some agency staff believed that the term ‘young carers’ should refer to young adults as well as minors. They noted that many in their early 20s continue to provide care for a family member, whether they live in the family home or not, and that many of the issues that arise when minors are the carers also arise for young adults. However, while acknowledging that this group may be missed by this study’s sample, nonetheless, one important rationale for retaining this focus is that the status of being a minor has significant consequences for the young carer, in particular concerning the supports they can receive, how caring will impact on their lives and how they can be identified. Moreover, although caring can play a positive role in normal childhood development, inappropriate caring can pose a threat to the same developmental process.

## Identifying and accessing young carers

One consistent finding from the literature is that the ‘invisibility’ of young carers is a key issue and so identifying and gaining access to young carers is a problem as well (Thomas *et al.*, 2003; Banks *et al.*, 2002a; Aldridge and Becker, 2003). The identification of young carers is made difficult because (1) young carers (and their families) often do not refer to themselves as ‘young carers’, either because they see this caring as ‘normal’ or because they fear acceptance of the term may encourage unwanted interventions from social services; and (2) professionals underestimate the prevalence of young carers, the tasks they perform and their levels of responsibility. Both facts suggest that there is a lack of awareness about young carers and a lack of appropriate services for them, as well as a fear of child protection interventions. It may be that service providers are unwilling to approach families about the issue of young carers since they know this will raise fears of unwanted interventions (Roche and Tucker, 2003). At the same time, the needs of young carers at present do not come ‘on the radar’ of either statutory or non-statutory, voluntary agencies.

How is awareness to be raised about young carers? Some agency staff believed that awareness-raising is needed before services are developed so as to include young people in a consultation process on the impacts of caring and the supports needed. Others believed that it is unjust to raise people’s awareness of a need for services without also providing access to the services, and that therefore awareness-raising should not occur until there are services in place to meet the needs of young carers.

Any attempts to gain access to young carers in the near future would have to replicate the methods adopted in this study. The research team generated all referrals, bar one, through close collaboration with agency staff (gatekeepers) over a lengthy period. Children and young people did not identify themselves as young carers – they did not respond to a media campaign or a nationwide distribution of information about the study. However, young carers reported enjoying and benefiting from peer support from fellow-young carers and many young carers looked for support and advice from adults, in particular from teachers or school principals. This suggests that young carers in Ireland would not be averse to seeking support from the equivalent of the UK’s ‘young carers projects’ and/or mentors, and therefore they may be encouraged to come forward and identify themselves in and through such programmes.

At present, there is no national database of young carers. However, there is also no legal obstacle to a person below the age of 18 being placed on a regional or national HSE database of informal carers, which could help raise awareness about young carers and facilitate accessing them. HSE carer departments have begun to establish databases for adult informal carers at a regional level and there are strong grounds for including young carers on such databases. Moreover, similar efforts could be made in the non-statutory sector. As is the case with any data collected from children and young people, however, the information must be kept securely and used only for the purposes for which it was collected.

Young carers themselves would benefit from awareness-raising programmes. Participants in the study reported that they had not, in the main, received any advice or information about caring or the care needs of their relatives from health professionals. One young carer (P6) explicitly stated that she felt she had been left to her own devices in this respect. Some agency staff also argued that the process of accessing young carers should be simultaneous with the process of providing services to young carers, and therefore the question of service provision needs to be addressed as well.

In the UK, there is a national system of associations to represent the interests of, and provide services to, young carers (Butler and Astbury, 2005; Dearden and Becker, 2004). These ‘young carers projects’ provide young carers with the opportunity to meet other children and young people in similar situations as themselves, and they also provide access to information and advice. However, as many of the participants in this study made clear, children and young people also benefit from taking part in activities that have nothing to do with their caring role, whether this is sport or music or a youth club. As one youth worker observed in the study, ‘the big thing is about letting them be kids, letting them be normal’. It has also been noted that children

and young people may be less inclined to respond to traditional methods of identification and, in particular, they may shy away from face-to-face encounters with what are perceived to be bureaucratic organisations; instead, they may prefer to use more 'modern' methods, in particular web-based approaches. Non-conventional methods used in other countries to identify young carers include on-line social networking and dedicated young carer websites.

## Impacts of caring on carers

Some researchers have argued that in recent studies on young carers the negative impacts of caring have been exaggerated and in doing so, a new 'welfare category' has been created (Parker and Clarke, 2002; Olsen, 1996 and 2000). The findings from interviews with young carers in this study do indeed show that caring can have positive impacts, but they also make clear that the negative impacts of caring can be significant. Moreover, in many of the interviews, it could be inferred that caring had led to more positive impacts than negative impacts because of the ways in which the young carer was supported, both by informal networks and by formal services.

In a number of cases, young carers were helped by parents and teachers to ensure that caring did not hamper their education, but in other cases, caring led to absences from school, distraction while at school and even early school-leaving. As one young carer said, if there was a crisis at home she would leave school immediately – 'School would be the last thing'. Many young carers were deeply involved in sport and music and kept in touch with friends, but once again, others did not have time for normal childhood socialising and in some cases they felt ostracised from their peers because of their caring role. The tasks performed by most carers were not physically demanding, but one young carer was absent from school with a back injury, another worried about having to lift her mother and many reported losing sleep. It was often the case that young carers explicitly stated they were more than happy to care for their sibling or parent. However, many were anxious and worried about how the condition of the person in need of care would develop and whether they would have to continue to provide care as an adult, while some resented the way that caring restricted their freedom.

The literature on young carers emphasizes that the impacts of caring are not uniform or homogeneous (Lloyd, 2006) and this is borne out in the interviews conducted with young carers. The impacts of caring on the young carer were, in part, influenced by the nature of the need for care: some, for example, needed help with toileting, others with mobility and yet others required emotional support. The nature of the illness or disability also affected the types of relationships that can be formed between the carer and the person cared for. Other research suggests that caring can reinforce family bonds (Aldridge, 2006) and again the study bears this out, with most young carers reporting that they felt 'closer' to the person cared for as a result of their caring role. However, this was not always the case: one young carer felt resentment for her caring role and worried about whether she would have to continue to care in the future, while another young carer noted that her brother's autism created a need for care that led to greater closeness, but also created obstacles to communication that, in turn, prevented closeness. The impact of caring was influenced also by the relationship to the carer of the person in need of care: one young carer felt much closer to his father after the death of his mother, while another did not feel close to his mother whenever she suffered a relapse in her mental illness.

The impact of caring on the young carer was also influenced by mediating factors, in particular, household structure, employment, the amount of space and privacy available in the house and access to formal services. As the literature has shown (Aldridge, 2008), employment is a potentially important influence on the support that is available for young carers and for the people in need of care, and this is supported by the findings of this study. Employment influenced the amount of income available in the household to help with caring and also the time available for adults (as opposed to their children) to perform caring tasks. At the same time, often an adult's ability to hold down employment was affected by their need for care. Most of the young carers in the sample caring for a parent did so in a one-parent household without any adult in paid work.

A clear gender dimension to caring emerged from the study. While the boys in the study did care for brothers, fathers and in one case a mother, some of the girls in the study cared for their brothers as well. In some families, one girl took on the bulk of caring tasks, even though her brothers were present and in a position to help, and one such young carer was clear that she felt her brothers did not carry a fair share of the caring burden. Agency staff also advised the research team that the gender division of labour may be more pronounced in minority cultures. Nonetheless, the boys who took part in the study performed the full range of caring tasks and some were also primary carers.

Another important finding is that caring in and of itself is significant. The literature on young carers has shown that young people are impacted in various ways by their caring role (Morrow, 2005; Grant *et al*, 2008). The interviews in this study show that young carers were affected in significant ways by caring, even if they did not live in poverty, or did not care for a parent, or were not a primary carer or were not involved in intimate care. How the family deals with the need for care is therefore crucial. In some families, the young carers told the research team they were shielded from intimate caring tasks, but this did not always happen. In some households, there was a great deal of discussion concerning the care need, but one 15-year-old carer reported she knew little or nothing about the condition in question, how it would develop and what treatment was required.

In the literature on young carers, 'intimate' care is an important and controversial topic (Hill, 1999; Altschuler, 1997; Earley and Cushway, 2002). It has been noted that such caring tasks can be inappropriate for young people. This is so in particular if the young carer is caring for a parent or if a female young carer is caring for a male relative (and vice versa). The worry that has been expressed is that such intimate care can lead to the 'parentification' of the young carer, i.e. that the young carer ceases to experience life like a child and instead exchanges roles with the parent(s) in the household, thereby potentially harming their own emotional and psychological development (Hooper, 2007).

Although it is important not to exaggerate the negative impacts of caring, it may be the case that some young carers are asked to do too much, too young. In such situations, there is a legitimate fear of 'over-functioning'. The vast majority of young carers in the study reported feeling 'more mature' than friends of the same age. This meant different things in different situations: either they had more responsibilities, or they were more aware of disability and illness issues, or they put the interests of others first (as happened in many cases). Some young carers had developed a more 'adult' perspective in that they were more aware of everyday responsibilities (although none of the young carers had a clear idea of the family's finances). It also meant that some young carers had less time to be 'child-like' and to enjoy their youth without excessive worries. In some cases, however, it was simply the case that the young carers had a finely developed moral sense, i.e. a sense of other people's burdens and their entitlements.

Two very different scenarios can be developed to illustrate the positive and negative impacts of caring:

### Young Carer – Scenario 1

The first scenario is that of a teenage girl who cared for her mother with a physical illness. The young carer provided intimate and general care, and she was the primary carer in the home. The crucial facts in her situation are two-fold: first, she did not receive much support from other family members in the household; second, she did not receive many formal supports to help with the care of her mother and there was a clear need for more support in the form of home help, respite care, medical treatment for the person in need of care and household modifications to lessen the caring burden. The negative impacts in this case included absences from school and being unable to spend time with her peers and friends. Although she felt close to her mother because of the need for care, crucially, the ongoing obligation to provide intimate care was a continuous source of worry and anxiety for this young carer.

### Young Carer – Scenario 2

A quite different scenario is evident from the experiences of another young carer – a teenage boy caring for a number of siblings, all with intellectual disabilities. Although he too was heavily involved in intimate and general care tasks, the impacts of caring on this young carer were very different. His school work did not suffer as a result of his caring role. He had a very busy social life with friends, sport and music. He had received advice and information from professionals treating his brothers. Moreover, his parents were the primary carers in this household, but more importantly they supported him as a carer and as a young person. Both of his parents were also involved in a voluntary organisation that supports families living with intellectual disabilities. This young carer not only felt close to his brothers, he also wanted to make life easier for them. What is more, his informal caring extended beyond the family and took on a civic dimension as well, which indicated that for him caring was not just a familial duty but a social or civic duty as well.

These two scenarios draw attention to a number of potentially important and inter-related variables in the experiences of young carers. The two young people seem to receive different levels of informal support, from parents and siblings in particular, and in addition to this, formal service provision appears more comprehensive in Scenario 2, including professional support in the form of advice and information for the young carer. The latter's situation also appears to be one where there is greater awareness of the young carer's role and greater appreciation of its worth. The cumulative effect of all of the above is a marked difference in respect of the rights of the two young carers highlighted. This is the case concerning specific rights to express their views on matters that affect them and also rights to education, leisure and recreation, information and the highest attainable standard of health.

A note of caution, however, is required concerning how to read these two scenarios. They are intended as a heuristic device that should help bring to light and clarify the experiences of young carers. The two scenarios cannot claim to capture everything there is to know about the experiences of young carers in the Irish population, particularly since causal mechanisms have not been identified for the experiences of these young carers. However, the two scenarios do draw attention to a number of important variables in the experiences of young carers and also illustrate the differences between young carers at separate points on the continuum of caring.

### Supporting young carers

This study has found that young carers are 'invisible' because they, their families and the professionals involved are either not aware of the reality of young carers or do not use that term because of its perceived negative connotations. It has also found that caring by children and young people leads to a variety of impacts and that while there are some significant negative consequences, it is not the case that caring by children and young people is by definition inappropriate. It is therefore necessary to both raise awareness about the reality of young carers and also to provide supports to them. However, is it possible to raise awareness without exaggerating the negative impacts of caring and, as a result, stigmatising young carers? The evidence from this study suggests that the best way to proceed is to examine ways in which to support families *and also* to guarantee children's rights.

This study has looked at the various different supports that young carers *do* receive and *should* receive. The most common form of support received by young carers, according to their interviews, was home help and this was also the form of support that young carers most frequently requested. They also said that they do receive and/or wanted to receive respite care, more income support, medical treatment for the person in need of care, support from youth organisations and peers, school help, support from relatives inside and outside the home, transport and money for such things as home modifications. Home help lessens the burdens of the carer in the home, without



removing the need for this informal caring role. The same is true of respite care, which provides carers with some time away from their caring responsibilities. Support from relatives, transport and money for renovations should lessen the burdens of the carer; youth organisations and peer support should provide a social outlet for the carer; medical treatment in some cases can remove the need for care altogether, but often it will not have this result; and finally, help in school can minimise some of the negative educational impacts of caring.

Often, the services received by young carers, and the services they request, do not remove the responsibilities of caring from them. Although in many cases the burdens of caring can and should be lessened, interviews with young carers indicated that many are very happy to continue to provide care, although they are aware of the negative impacts of caring. In sharp contrast, many agency staff believed that children only provide care if and when services for the person in need of care are insufficient and that sufficient service provision would remove the caring responsibilities from children and young people. Two of the main findings from this study are:

- informal care, including care by children and young people, can be a valuable support for people in need of care;
- as the quality of informal support networks makes a big difference between positive and negative impacts for the young carer, young carers themselves benefit from informal supports alongside formal services.

The theory of 'family support' draws attention to the positive results to be derived from informal support, although it in no way neglects the importance of formal service provision. It suggests that children need concrete forms of support (i.e. practical help), but they also need emotional support, advice and guidance, and these they can get through informal networks of family, friends and voluntary organisations. The triadic relationship between child, family and community is important for the child's ability to establish relationships and therefore contributes to a child's development and coping capacity (Dolan, 2008, p. 85). Crucially, the child's role within these informal networks is active rather than passive. The child is an agent or player, and therefore must be 'resilient'. Resilience has been defined as '*good outcomes in spite of serious threats to adaptation or development*' (Masten, 2001, p. 228). Resilience is relevant to any discussion of how best to support children and young people who are impacted in negative ways by their situation, including young carers, because it focuses attention on how to harness the child's own capacities in overcoming difficult circumstances.

It is reasonable to infer from the interviews that many of the young carers in this study are resilient in their difficult circumstances. However, the interviews suggest that some caring situations undermine the family support needed by the young person. Some young carers reported that their caring responsibilities interfered with their education and social life, which may leave them disadvantaged as a result. Other young carers seemed to feel resentment or shame or anger because of their caring situation, which may have negative impacts on their emotional development. In many cases, therefore, children and young people will not be resilient without help from formal services, as well as from family, friends and the community.

The concepts of resilience and family support have been subject to close and critical examination. Some believe that the concepts do not allow a critical perspective to be taken on social reality. It is therefore important that an interest in building resilience does not blind one to the 'concrete awfulness' that some children and parents face (Canavan, 2008, p. 4). For example, some of the young carers in this study could not have functioned well without the home help and respite care they receive and also it is clear that they do not receive enough in the way of formal services. However, it does not follow that such families do not need informal supports as well. It is also important that this theory does not simply act as an ideological justification for an individualistic and market-oriented approach, blinding one to the importance of social structures and inequality in shaping people's opportunities and life experiences (*ibid*). However, what it does do is show that even when formal supports are there to lessen the impacts of inequality, the capacities of the child or young person must themselves be harnessed and fostered. Moreover, the multidimensional



nature of the concept must be recognised, so that resilience in one domain, such as education, is not taken to imply resilience elsewhere, such as emotional development (*ibid*). Indeed, it seemed that some of the young carers in this study were emotionally well-adjusted to their caring role, but were disadvantaged in other areas, in particular in education.

Finally, even if it is the case that many young carers will be best assisted by support from their families, in some cases the only way to protect the child's interests is to guarantee the child's rights as an individual. However, some believe that to guarantee children's rights may either undermine the authority of parents or pit the interests of young carers against those in need of care, for example, those with a disability. Yet, what morality requires is that we give 'equal consideration' to the 'like interests' of all (Singer, 1993, p. 21). What is crucial is to give due consideration to the interests of children, including young carers. It would not be legitimate to prioritise the interests of children to the exclusion of the interests of parents or those with a care need. However, if the interests of children are not given as much consideration as the similar interests of others, this is an unjust infringement of children's rights.

The issue of children's rights is also relevant to child protection issues and child protection concerns are raised by the experiences of some young carers. However, while some agency staff believed that all cases of young carers providing intimate care or acting as primary carers are, by definition, inappropriate, a more nuanced approach is to distinguish 'young carers' generally from young carers who are also 'vulnerable'. What is important is the quality of the experiences and relationships. Therefore, a child protection issue arises not because children are caring but only if this caring entails 'neglect' or 'abuse' of the carer. Children can be said to be 'neglected', according to one counsellor in this study, by comparing their situation with that of a 'normal' childhood in regard to education, social life and physical and emotional well-being.

What is necessary for normal childhood development, according to family support theory, are three forms or stages of 'recognition'. A supportive and caring family environment and friendships can, and should, lead to recognition in the form of enhanced resilience and self-confidence (Houston and Dolan, 2008, p. 460). When this form of support is missing, there are dangers of abuse of various kinds. In addition, more formal supports and recognition, both legal rights and 'acknowledgement' from the community, can also enhance the person's self-respect and self-esteem. In the absence of these formal supports, the individual may be excluded or have a low social standing. While recognition and support within the family is an end in itself, it also enables the individual to be independent and to enter civil society on an equal footing with others.

Those who take a 'child protection' approach may feel that 'family support' theory lacks the robustness needed to intervene in families where children are neglected and abused. However, there is no good reason to believe that the two approaches are incompatible. Often the best way to ensure that child protection issues do not arise in the future is to intervene early in families so as to support them and their informal networks. This is particularly relevant to the situation of the young carer. A young carer's situation would raise worries and concerns if the caring responsibilities interfered in a significant way with normal childhood development.

Another important question is whether it is possible to combine a children's rights approach with a commitment to family support. The findings of this study are that the interests of young carers are not being given due consideration if they are not supported in their caring role. It is for this reason that attention should be paid to children's rights. Children's rights should be 'prioritised' in the sense that children should not have to wait to receive a needed or wanted service until their parents or guardians decide to access that service for the child. The argument is that delays in meeting basic needs for children damage the interests of a child to a far greater extent than similar delays in respect of the needs of an adult, and this is the case because of the child's stage in the developmental process. Protecting children's rights in this way is not incompatible with supporting the child's family if the child is seen as an individual with entitlements, just like everyone else in the family. There are good reasons to say that children and young people cannot

enjoy all the rights that adults have. At the same time, as the literature review shows, it can be argued that as the capacities needed to exercise rights develop, so too should rights be enjoyed and, therefore, as children and young people mature they can be granted ever more rights. What is more, young carers obviously have developed many of the capacities needed to exercise rights.

The family support approach does not focus exclusively on informal support networks and interviews with young carers also highlight the need for better formal service provision. Much of the care provided by young carers happens in the home outside of standard support service hours (i.e. in the early morning, the evening and at weekends). This would suggest that support services are not available when needed or of the type needed, in particular home visitation and personal assistants. One way to marry a commitment to informal support networks with better formal service provision is to adopt a 'whole family' assessment framework. In such an approach, a family plan is devised, with input from all members of the family in conjunction with the professionals.

Finally, who is to take responsibility for funding, monitoring and delivering formal services to young carers? At present, carer departments in the HSE deal with young carers on an ad hoc basis only since their primary concern is with the adult carers in a household. If it can be shown that some young carers are primary carers and/or are providing intimate care, then there is a strong argument to be made that HSE carer departments should give equal consideration to these young carers and that they should be provided with the budget to do so effectively. What is more, even young carers who are not primary carers or who do not engage in intimate care are affected by their caring role and often are in need of services of some kind.

# 7 CONCLUSIONS

This study of young carers in the Irish population had three main aims:

- to examine mechanisms through which young carers (aged 5-17 years) in the Irish population can be identified;
- to explore the impact of caring on their lives;
- to identify ways in which they can be assisted.

In meeting these aims, the research team completed a comprehensive review of the literature on young carers, recruited a sample of young carers and agency staff as participants in the study, and conducted interviews with young carers and agency staff to provide data on the three key aims of the study. The difficulties encountered in identifying and recruiting young carers to the study – and the specific means whereby these difficulties were addressed – are, in themselves, key findings of the research.

## Literature review

National and international literature on law, policy and practice as related to young carers was first examined. It was found that while much could be learnt from the UK and Australia in particular, in Ireland there is no legislation or policy for young carers and there are no targeted services to meet the needs of young people as young carers. Although Ireland is a signatory of the UN Convention on the Rights of the Child – and many of its rights are highly relevant to supporting young carers – its provisions are not directly incorporated into Irish law.

The literature review also explored a number of key themes and debates in relation to young carers. Researchers have emphasized that young carers are to an important extent ‘invisible’ because they and their families and professionals tend not to accept this label and also because of a lack of services for young carers. They are a ‘hard to reach’ population and this has important implications for identifying and recruiting young carers for studies. Some researchers have argued that a children’s rights approach leads to a conflict between the interests of young carers and others, including those with an illness or disability. However, it can also be argued that the appropriate balance can be found between the rights of young carers and the rights of people with disabilities. It is also claimed by some researchers that the provision of intimate care by young carers and their status as primary (or main) carers lead to over-functioning and ‘parentification’. However, findings from this study indicate that even in such situations, there can be positive impacts for the young carer, although impacts will be positive only in so far as the child or young person is supported through both informal networks and formal services.

## Sampling and recruitment

Two different phases of sampling and recruitment were undertaken in this study. Phase 1 relied largely on written requests for referrals from agency staff, along with a nationwide information campaign. Only 6 referrals were generated from this phase. Phase 2 of recruitment was vastly more successful, generating a further 20 referrals. In this phase, the original purposive sample was combined with convenience and snowballing sampling methods. The second phase was a success largely because researchers established good working relationships with agency staff, explaining the research to them, in particular the definition of ‘young carer’, and the purposes of the study. Success in recruiting young carers was due in large part to agency staff acting as gatekeepers to children and young people.

Recruitment to any further study of young carers in Ireland will still face difficulties, however, as young carers continue to be, to a great extent, ‘invisible’. The recruitment phase of the study found that:

- many professionals providing services to members of a family in need of care did not know that a young person within the home was a carer;
- the use of the term ‘young carer’ itself proved challenging since people associated the term exclusively with primary carers and/or intimate care;

- often young people providing care is a sensitive issue for both parents and their children, and for this reason both parties are often happy for the care work to be kept private or not brought to the attention of the ‘authorities’.

Findings from interviews with young carers and agency staff also showed that young carers are ‘invisible’ for a number of reasons:

- there are no services designed specifically for young carers and there are no organisations specifically representing their interests;
- there is a lack of awareness among professionals concerning young carers and gaps exist in agency staff’s knowledge about the prevalence of young carers, the tasks they perform, the age at which they begin caring and their levels of responsibility;
- there are no databases in the statutory or non-statutory sectors recording the details of young carers;
- young people, their families and professionals are reluctant to use the term ‘young carer’, mainly due to perceived associations with such negative connotations as inappropriate care and onerous age-inappropriate responsibilities, and/or the stigmatisation of the young carer, their family and the illness or disability involved.

## Key findings

Important findings from this study concern the definition of young carers, mechanisms for the identification of young carers, the impacts of caring on carers and the supports that are, and should be, provided to young carers.

### Defining young carers

The research team proposed the following definition of ‘young carers’ for this study:

A young carer is a child or young person under 18 years whose life is affected in a significant way by the need to provide care for a family or household member who has an illness, disability, addiction or other care requirement. This may include a child or young person who provides direct personal care or who takes on a supportive role for the main carer. A young carer may carry out domestic tasks or may provide general, intimate or emotional care. These needs may arise on a regular or on an occasional basis. There is therefore a continuum of caring and as a result the service requirements of young carers will vary. It is important to differentiate between a level of caring that has largely positive consequences and a level of physical or emotional caring that impairs the child’s health, development or welfare.

As defined here, the term ‘young carers’ refers to a broad range of experiences and a wide spectrum of caring situations. It includes primary and secondary carers. It incorporates those who provide intimate and/or general care, as well as those who only perform domestic tasks. The aim here is to capture within one concept all those whose lives are affected in some significant way by the care needs of another household member.

The term ‘young carers’ as defined here does not refer to those young adults who continue to provide informal care within the family home although they are no longer minors. Findings from interviews with agency staff show that such adult carers are already recognised as informal carers and can receive services as carers, although it does not follow that they receive these supports consistently. Findings from interviews with young carers also show that caring by a minor can be a positive experience, but also that it leads to negative outcomes when the child or young person does not receive the supports necessary for normal childhood development.

## Identification of young carers

This study can conclude that young carers are a 'hard to reach' population. Young carers are, to a great extent, 'invisible'. There are no mechanisms in place in Ireland to identify them because they themselves, their families and professionals do not use the term 'young carer' and there are no services designed for them. Either it is felt that caring is just a normal part of family life and therefore is no different from normal childhood, or alternatively, the role of young carer is perceived to be stigmatised and families are afraid or ashamed to use the term.

This study can conclude that the solution to the 'invisibility' of young carers is a two-fold process, involving:

- services provided to young people as young carers;
- awareness raised about young carers, without further stigmatising their role.

Awareness-raising can be achieved by:

- giving presentations in schools;
- encouraging teachers to take an interest in young carers in their classrooms;
- establishing websites that young carers can visit;
- encouraging young carers to be advocates for themselves.

It is also important to raise awareness among professionals working in services relevant to young carers. However, services will be provided to young people as young carers *only if* resources are allocated for this purpose and if existing organisations are given or assume responsibilities for providing assistance to young carers.

## Impacts of caring on carers

In this study, young carers themselves spoke of the impacts of caring on them. The study can conclude that there is a broad continuum of caring and a wide variety of caring situations. It can also conclude that it is a mistake to equate intimate care or primary care per se with 'over-functioning' and 'parentification'. Although it is the case that caring can impact negatively on the young carer and the negative impacts can hinder the child or young person's normal development, nonetheless, this study has found that such over-functioning is a possibility only in so far as formal and informal networks of support are insufficient.

Two very different scenarios were developed in Chapter 6 to illustrate the positive and negative impacts of caring. Caring Scenario 1 was based on the experiences of a teenage girl caring for her mother with a physical illness. Caring Scenario 2 was based on the experiences of a teenage boy caring for his 3 siblings with intellectual disabilities. In both cases, intimate and general care were provided, although only the teenage girl was a primary carer. In Scenario 1, the young carer did not receive enough support, whether formal or informal, and indeed there was little acknowledgement of her caring role within her family or among service providers. Although she reported feeling closer to her mother as a result of her caring role, concern is raised about her enjoyment of basic rights, in particular the 'best interests of the child principle' and more specific rights to education, leisure and recreation, information and the highest attainable standard of health. In contrast, it was clear that in Scenario 2 the teenage boy received a great deal of support from family and professionals. His parents were primary carers in the home, but also involved in an agency to support families living with disability, and the young carer received information and advice from professionals. His caring role was acknowledged and its value recognised. He had time to be with friends and join sports clubs, and also cared informally outside the home. In this second scenario, caring was associated with positive outcomes in education, social life, maturity and compassion.

These two scenarios illustrate and support the study's conclusion – that the quality of informal support networks, formal service provision, the protection of the child's rights and the awareness and recognition of the young carer's caring role greatly influence whether caring has negative or positive impacts for the carer.

This study can conclude that:

- there is a continuum of care and, therefore, the needs and experiences of young carers vary;
- caring by children and young people can be a valuable and positive role, but also it can lead to negative consequences when informal support networks are weak, formal service provision is insufficient, rights are not protected and there is little awareness of the caring role.

### Supporting young carers

This study has found that young carers will be best supported in the following ways:

- develop services designed specifically for young carers;
- protect the rights of young carers;
- harness and foster informal networks of support;
- raise awareness about young carers.

It would be unfair to young carers and their families to embark upon a project of raising awareness about young carers without also providing services to them. Moreover, awareness-raising is also required among professionals before services can be provided. Since gaps were apparent in agency staff's knowledge of young carers, awareness must also be raised among those working in this area.

The objectives of protecting rights and promoting informal support networks need not be contradictory. It is possible to both protect the rights of young carers as individuals and at the same time support the family. Protecting the rights of young carers simply means to give 'equal consideration' to the 'like interests' (Singer, 1993, p. 21) of young carers along with all other individuals. It does not mean to prioritise the interests of young carers at the expense of the interests of other members of the household – their parents or those with a care need. In sum, the interests of children and young people in this situation must be given as much consideration as the similar interests of others.

It was noted in interviews with agency staff that often it will be important to protect a child or young person's rights because their developmental needs are urgent and the need must be met as soon as possible and, therefore, the young carer should often receive the support regardless of whether the parent(s) wishes this to happen. As their capacities for making decisions develop, the views of children and young people should be taken into account in the provision of formal services.

It is the case that young carers *want* to receive more formal supports. Interviews with them show that such services as home help, respite care, income support for the family, money for renovations and treatment and education are crucial to the welfare of the young carer, as well as to the rest of the family. However, such services should also enable informal networks to develop and furthermore formal services can directly bolster such informal networks.



# 8 AREAS FOR CONSIDERATION

This is the first national qualitative study of young carers in Ireland. While it is both exploratory and preliminary, it does nevertheless provide an insight into the lives of children and young people who provide care in the home and uncovers the reality of their situation. The findings corroborate international findings in relation to young carers elsewhere (Aldridge, 2008; Butler and Astbury, 2005; Dearden and Becker, 2004; Roche and Tucker, 2003) and represents, therefore, a significant starting point for Irish policy, service and research in this area.

The conclusions of this study are informed by interviews conducted with 26 young carers from across the country and 30 staff from agencies involved in providing services to children and families. The participating young carers ranged in age from 5 to 18 years, they performed a variety of tasks, took on different levels of responsibility, responded to various care needs and also differed significantly in respect of the supports and assistance received.

Building on the findings of the study, the following discussion first presents a working definition of 'young carers', as well as the type of care provided, the level of responsibility assumed and the health problems of those who are in receipt of care from children and young people. The positive and negative impacts of caring are also identified.

Following on from this, a number of areas for consideration by policy-makers and service providers are recommended, including mechanisms for the identification of young carers and supports for them. In particular, and to ensure the rights of the child, emphasis is placed on awareness-raising and the importance of informal as well as formal supports.

## Proposed working definition and definitional materials

Interviews with young carers in this study uncovered a continuum of caring and, taking their views into account, a new definition of young carers is suggested below. It builds on the definitions employed by Gray *et al* (2008), Frank (2002) and Thomas *et al* (2003). As the area becomes better understood, it may be possible for this definition to be more nuanced and limited. But for now, a definition that is comprehensive and inclusive can serve young carers better. The proposed definition is as follows:

A young carer is a child or young person under 18 years whose life is affected in a significant way by the need to provide care for a family or household member who has an illness, disability, addiction or other care requirement. This may include a child or young person who provides direct personal care or who takes on a supportive role for the main carer. A young carer may carry out domestic tasks or may provide general, intimate or emotional care. These needs may arise on a regular or on an occasional basis. There is therefore a continuum of caring and as a result the service requirements of young carers will vary. It is important to differentiate between a level of caring that has largely positive consequences and a level of physical or emotional caring that impairs the child's health, development or welfare.

Young carers who took part in this study performed such tasks as:

- domestic help;
- general care, including help with feeding, medication and mobility;
- providing psychological or emotional support;
- intimate care, involving toileting, dressing and bathing;
- childcare, i.e. looking after siblings;
- other types of care, including seeking support from service providers, translating and interpreting information, helping with paying bills, post or telephone calls.

These tasks are similar to those identified elsewhere in other international studies, including Dearden and Becker's 2004 survey of over 6,000 young carers in the UK.

The health problems of those with care needs, being cared for by young carers, included:

- behavioural or learning difficulty;
- combined intellectual and physical disability;
- physical illness;
- mental illness;
- drug or alcohol addiction;
- sensory impairment.

Again, studies on young carers in the UK have reported similar findings (Dearden and Becker, 2004).

Young carers in this study identified different levels of responsibility and these can be categorised according to whether they were primary or secondary carers, defined as:

- a primary carer is the predominant carer within the home;
- a secondary carer helps the primary carer to provide care.

A similar categorisation has been used in other studies, with some emphasizing that primary carers are in the minority among young carers (Gaffney, 2007).

Both positive and negative impacts of caring were identified in this study. Specific negative impacts identified by young carers themselves and other stakeholders included:

- absences from school or distraction at school;
- feelings of social isolation because of a lack of time for leisure and friends;
- physical illness;
- being 'on call' all the time;
- boredom, worry and resentment.

Positive impacts identified by young carers themselves and other stakeholders included:

- greater connectedness or closeness to the person cared for;
- maturity;
- compassion.

Further longitudinal research is required to better understand the potential long-term impacts of caring on the young carer.

## POLICY ISSUES arising

The following policy issues have been identified as critically important in developing services for children and young people who are acting as carers in their home.

### Coordinated cross-sectoral, multidepartmental and multiagency approach

It could be argued that while no individual Government department, agency or service provider has overall responsibility for young carers, there are many different organisations that could potentially support this group of children and young people. A key policy question arising, therefore, is how can young carers be supported, given the context of multiple services, sectors, agencies and providers within which they operate? This question can best be addressed by adopting a cross-sectoral, multidepartmental and multiagency approach. Consideration would need to be given to the context within which this can take place and the need for existing budgets to be re-examined in light of the new focus on young carers. Such approaches have been adopted in order to deal with other issues of concern; elsewhere, the creation of a working group, including stakeholders from the statutory and non-statutory sectors, has been found to be successful in developing and implementing policy and services in complex areas – see, for example, the *Report of the Working Group on Elder Abuse* (Department of Health and Children, 2002). The development of the new National Children's Strategy (forthcoming, from the Office of the Minister for Children and Youth Affairs) may also provide a mechanism through which this issue can be addressed.

### **Raising public awareness of children and young people as carers**

It is clear from this study that young carers are a hard-to-reach group within the general population and to an important extent 'invisible'. Similar findings have emerged from studies in Australia (Morrow, 2005) and the UK (Thomas *et al*, 2003). The identification of young carers and accessing them requires careful consideration and efforts to identify them should take account of the following principles:

- It is essential to raise awareness about young carers without exaggerating the negative impacts of caring and, as a result, stigmatising them.
- Young carers must themselves identify with the label, but also awareness needs to be raised among parents/guardians and professionals.
- Raising awareness about young carers must go hand in hand with the provision of services designed for young carers.

### **Ensuring children and young people have a voice in matters that affect them**

As part of a rights-based approach, the importance of ensuring children and young people have a voice in matters that affect them must be recognised. Any developments taking place – nationally, regionally or locally – to deal with issues relating to children and young people as carers should ensure that the voices of young carers are heard and taken into account.

### **Recognising the continuum of care and diversity of supports required**

The continuum of caring identified by children and young people in this study suggests that any policy and service response to young carers should acknowledge the variety of caring situations and the diversity of supports needed. This includes a recognition that different cultures can have different understandings of caring roles, which needs to be taken into account in future developments.

### **Improved understanding of children as carers**

Consideration needs to be given to improving our understanding about the number of young carers in Ireland since it is clear from the findings of this study that caring responsibilities can commence in early and middle childhood. In the UK, information about children and young people who have caring responsibilities is collected through the Census about those aged 5 years and older. A similar type of approach could be adopted in the Irish context.

Consideration also needs to be given to understanding the various contexts within which young carers can be identified and the interventions that are effective in supporting them in this situation.

## **SERVICE ISSUES arising**

The findings from this study suggest that service responses designed to support and assist young carers, and to ensure their rights, should combine formal service provision with awareness-raising and a family support approach.

Young carers are likely to have needs in the following areas because of their caring role:

- information about services that can assist them and assist the recipient of care;
- support in the home;
- help with school from teachers;
- emotional support and advice from mentors or service providers;
- time to be with friends;
- time to take part in sports and other activities or interests.

Much can be learnt from the research by Roche and Tucker (2003) in the UK, which shows that services rarely responded to the child or young person's needs as a carer and instead usually only intervened when there was a child protection concern. Also, there is much to be learnt from successful developments elsewhere: a number of such projects were analysed in the course of this study and could prove helpful in the Irish context, with the following priorities identified.

### **Create mechanisms for young carers to make contact with service providers**

It is essential that young carers are recognised and encouraged to come forward so that their needs can be addressed. One example identified in the course of this study were the 'young carers projects' in the UK, where self-referrals by young carers can be encouraged by establishing dedicated young carers' websites and organisations (Butler and Astbury, 2005; Dearden and Becker, 2004).

Other mechanisms can include:

- actively raising awareness about young carers by, for example, a targeted information campaign in primary and secondary schools;
- increasing the profile of potential caring responsibilities of young people among professionals in statutory and non-statutory bodies;
- identifying and raising awareness about the characteristics of young people who act as carers. For example, young people in this study indicated that they were sometimes (or regularly) absent from school, were distracted while at school, were unavailable for extra-curricular activities and suffered from illness or injury as a result of their caring role. Agency staff interviewed in the study also believed that young carers may have behavioural or psychological problems if their caring role is not properly managed. In assessing children with these characteristics, therefore, some consideration should be given to whether they have caring responsibilities as well.

### **Proactively identify young carers where there is already a known care need**

A proactive approach to seeking out and identifying young carers in households where there is a known care need should be taken. Successful interventions elsewhere have focused on extending the remit of existing organisations that already provide services or that are in contact with people who have caring needs. These organisations can also represent and assist in meeting the needs of young carers. Where organisations are already providing services to adult carers, the following interventions should be considered:

- ensure policies and procedures include reference to young carers;
- develop services suited to the experiences and needs of young carers;
- give young carers a voice, e.g. through the facilitation of young carer advocacy.

### **Develop referral pathways to supports**

The findings from this study suggest that it is important for any service providers in contact with children and young people, but particularly those involved with young carers, to develop referral pathways to others who can provide support. Areas of support identified in this study include youth work, sport and recreation, financial support, mentoring, therapy and services for the person with the care need.

### **Ensure young people are given a voice in developments taking place**

It is crucial that the voice and opinions of young carers are heard in the development of services, so that these will be relevant, applicable and utilised.

### **Develop suitable materials to inform young people**

Consideration should be given to the development of materials that target young people, with an emphasis on the following aspects:

- recognise the characteristics of children and young people who have caring responsibilities, the types of care provided and the recipients of care;
- encourage young people to come forward and let someone know about their caring role: this might involve, for example, telling a teacher or school principal, a friend, a professional helping the person in need of care in the home or someone from a carers' organisation or youth organisation;
- actively seek out supports, whether they are informal (from family and friends) or formal (e.g. from a healthcare worker or teacher);
- identify potential areas of need, including information needs about services and the importance of making time for themselves, of having friends, of looking after their own physical needs and of taking part in activities outside the home;
- provide information about ways of making contact with relevant organisations and referral pathways to support.

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# APPENDICIES



## Appendix 1: Results from NUI Galway's e-Knowledge portal

### 1. Search for 'young (and) carers' by subject field

e-Resource Name	Status	Hits
NUI, Galway Library Catalogue	Done	0
Business Source Premier (EBSCO)	Done	0
JSTOR	Done	0
Academic Search Premier (EBSCO)	Done	0
Zetoc	Done	7
Web of Science (ISI)	Done	199
ScienceDirect (Elsevier)	Cannot parse result	
OmniFile FT Mega (Wilson)	Done	0
<b>Combined results</b>		<b>206</b>

### 2. Search for 'young (and) carers' by any field

e-Resource Name	Status	Hits
NUI, Galway Library Catalogue	Done	7
Business Source Premier (EBSCO)	Done	23
JSTOR	Done	0
Academic Search Premier (EBSCO)	Done	385
Zetoc	Done	144
Web of Science (ISI)	Done	199
ScienceDirect (Elsevier)	Cannot parse result	
OmniFile FT Mega (Wilson)	Done	108
<b>Combined results</b>		<b>866</b>



## Appendix 2: Young Carers' Recruitment Phase 1: List of agencies contacted

### Recruitment Phase 1: October 2008 – March 2009

#### NON-STATUTORY SECTOR

- Carers Association: National Office
- Caring for Carers Ireland
- Barnardos
- Foróige
- St. Vincent de Paul
- ISPC
- MS Ireland (Multiple Sclerosis Society)
- Irish Association for Spina Bifida and Hydrocephalus
- Irish Wheelchair Association
- Arthritis Ireland
- Irish Cancer Society
- Irish ME/CFS Support Group
- Irish Motor Neuron Disease Association
- Aspire (Asperger Syndrome Association of Ireland)
- Aware (support for people with depression)
- Mental Health Ireland
- Schizophrenia Ireland
- Headway (Acquired Brain Injury)
- Brí (Brain Injury Ireland)
- Brainwave (The Irish Epilepsy Association)
- Ahead (Association for Higher Education Access and Disability)
- Al-Anon/Alateen
- Diabetes Federation of Ireland
- Post Polio Support Group
- Volunteer Stroke Scheme
- The Alzheimer Society of Ireland
- Age Action Ireland
- Inclusion Ireland (National Association for People with Intellectual Disabilities)

#### Umbrella Groups

**Note:** All agencies that are members of these groups were indirectly contacted by the umbrella organisation.

- Care Alliance Ireland
- Children's Rights Alliance
- National Federation of Voluntary Bodies for People with Intellectual Disabilities
- Disability Federation of Ireland
- Youth Work Ireland

#### STATUTORY SECTOR

##### HSE Carer Services

- Manager Carers Department, HSE West
- Coordinator of Services for Carers, HSE Dublin Mid-Leinster
- Carers Development Officers, HSE West
- Development Manager for Carers, HSE South

##### Other Statutory Sector Services

- Disability Services Department, HSE West
- National Disability Authority
- People With Disabilities Ireland

## Appendix 3: Young Carers' Recruitment Phase 2: List of agencies contacted

### Recruitment Phase 2: April 2009 – July 2009

#### NON-STATUTORY SECTOR

- Carers Association: Regional Centres – 16
- National Parents and Siblings Alliance (autism and other intellectual disabilities)
- ACT (Action for Children and Teenagers, a parents' representative group for children cared for by the Brothers of Charity)
- SHINE (supporting people affected by mental ill health)
- GRA (Autism)
- Brothers of Charity
- Ability West
- Enable Ireland
- National Dystrophy Ireland
- Youth Advocate Programmes Ireland
- Irish Hospice
- Cystic Fibrosis Association
- Bray Lakers (serving people with special needs)
- Bluestack Foundation (children with special needs/disabilities)
- Forum Connemara (Community Development Organisation)
- Galway Traveller Movement
- Big Brother Big Sister

#### STATUTORY SECTOR

Key contacts were made with personnel from the following sectors/sections in the HSE and in many cases, through these contacts, information on the study was circulated on a regional and national basis within their relevant sectors/sections.

#### HSE

- Public Health Nursing
- Social Work
- Family Welfare Conference Coordinators
- Special Needs Counsellors
- Neighbourhood Youth Project Workers
- Family Support Services
- Child Care Services
- Out Reach Nurses
- Disability Services
- Psychiatric Services

#### Other

- Equality Authority
- Centre for Disability Law and Policy, NUI Galway

## Appendix 4: National information campaign

### POSTER

I help with my little sis Sandra  
Sandra's got Down Syndrome  
I help  
the t  
secot  
up an

I care for m  
He's got autism  
He can't talk m  
he's really good o  
I have to help him a  
and make sure he doe  
not harm himself.

dad drinks an  
depressed  
I put him t  
bed and get  
dinner rec

# DO YOU care?

Lots of young people  
care for a member of  
their family who have  
a disability or health  
problem.

**you are not alone  
share your story with us**

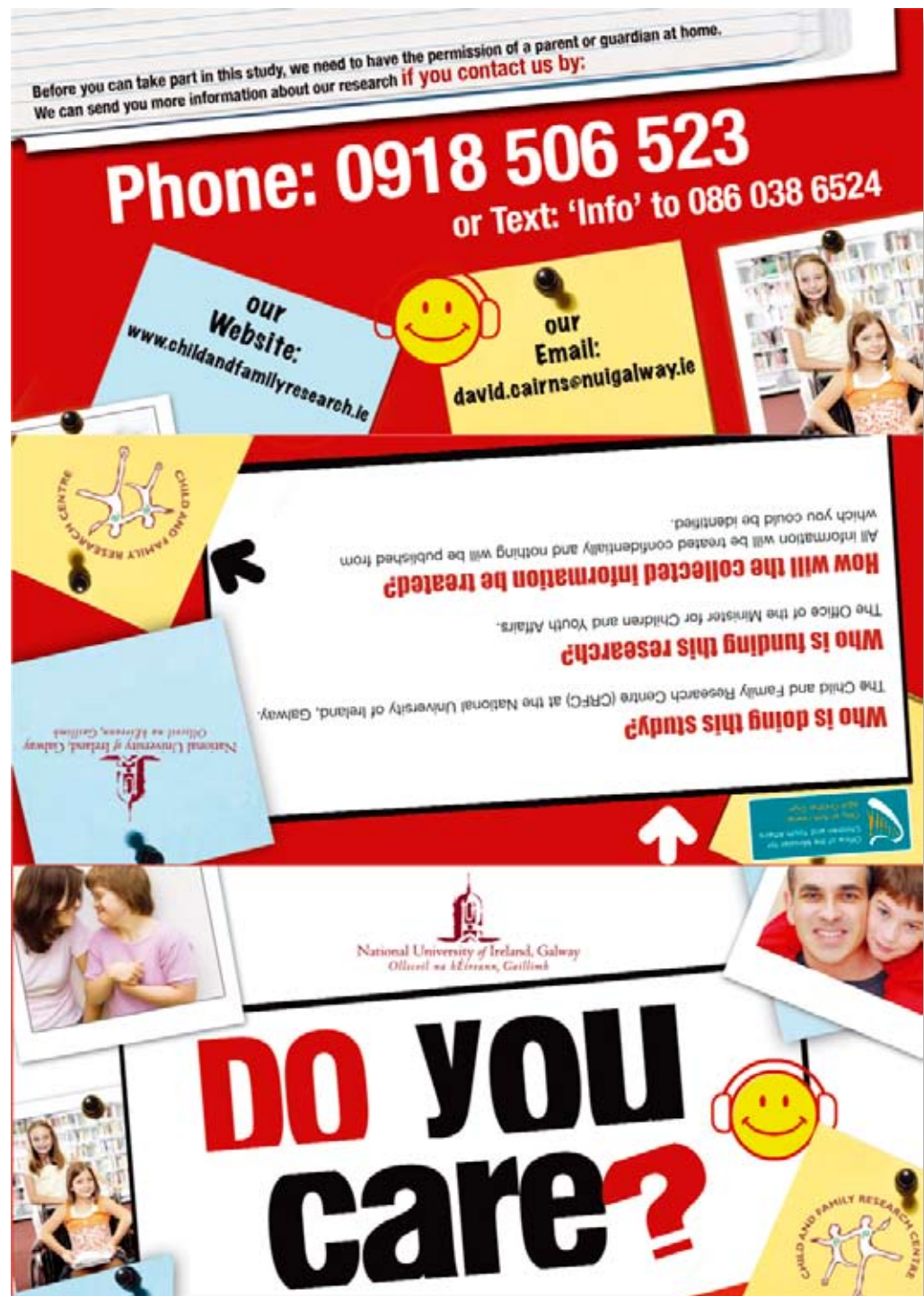
If you know someone between 5 and 17 years old who helps look after a family member at home, we would like to hear about their experiences. We are doing this research to learn more about what it is like for young people who care for a family member and see if anything can be done to help them. If you or somebody you know would like to take part in the study, contact us through any of the ways listed below.

our website:  
[www.childandfamilyresearch.ie](http://www.childandfamilyresearch.ie)

**PHONE: 091 495731**  
**Text: 'Info' to 086 038 6524**

our email:  
[david.cairns@nuigalway.ie](mailto:david.cairns@nuigalway.ie)

## FLYER



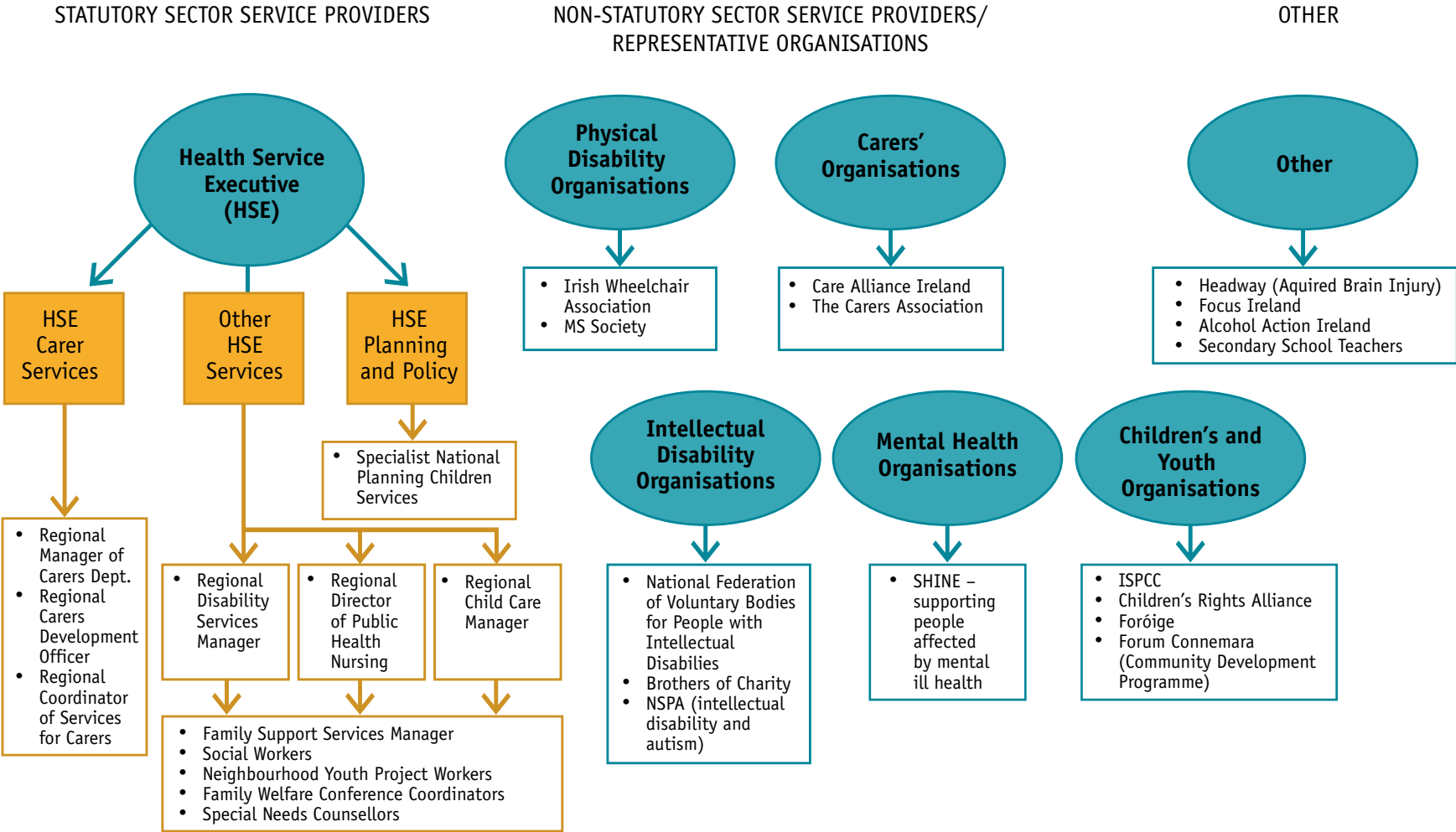
### Distribution of posters and flyers

The following received either posters or flyers, or both:

- schools – all 760 post-primary schools in Ireland;
- youth cafés – 17 across Ireland;
- youth services and organisations – 21 across Ireland;
- youth information centres – 37 across Ireland;
- ISPC Regional Centres – 10;
- Foróige's Regional Offices – 17;
- Family Resource Centres – 106 across Ireland.



# Appendix 5: Sample of agency staff contacted



## Appendix 6: Interview schedules for young carers\*

### (A) Interviews with children AGED 5-11

#### Part 1: Personal background

1. What is your age? \_\_\_\_\_ years old
2. Are you male or female? ☐ Male ☐ Female
3. What is your country of birth? \_\_\_\_\_
4. Whereabouts do you live? \_\_\_\_\_
5. Who lives with you at home? \_\_\_\_\_
6. If working, what do your parent(s)/guardian(s) do for a living?  
Mother \_\_\_\_\_  
Father \_\_\_\_\_  
Guardian \_\_\_\_\_

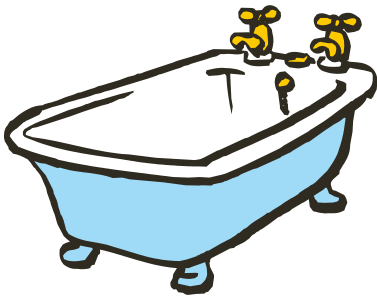
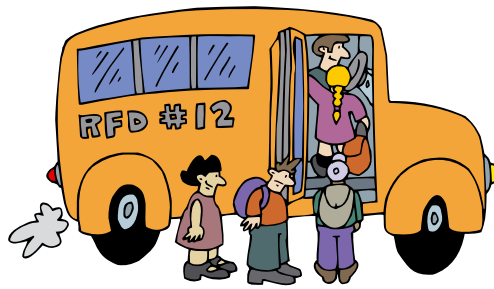
#### Part 2: Looking after someone at home

1. **Helping at home** – Do you ever do any of the following:



\* For copyright reasons, the images reproduced in Appendix 6 are not the original images used in the interview schedules.

2. **Caring tasks** – Do you ever do any of the following that you see in these pictures:





**Part 3: At school**

Do you ever find yourself in any of the following situations at school:



## (B) Interviews with children AGED 12-17

### Part 1: Personal background

1. What is your age? \_\_\_\_\_ years old
2. Are you male or female? ☐ Male ☐ Female
3. What is your country of birth? \_\_\_\_\_
4. Whereabouts do you live? \_\_\_\_\_
5. Who lives with you at home? \_\_\_\_\_
6. If working, what do your parent(s)/guardian(s) do for a living?
 

Mother \_\_\_\_\_  
 Father \_\_\_\_\_  
 Guardian \_\_\_\_\_

### Part 2: How do you spend your day?

Can you talk about how you spend your day:

- At school
- At home
- Social activities

### Part 3: Looking after someone at home

1. Who do you look after at home?
2. Why do they need help?
3. For how long have you been helping them?
4. Were you asked to do this or did you offer to do it?
5. And how did you feel having to do this?
6. Did you get any advice or support?
7. How do you help at home:

	Once or twice	Fairly regularly	Very often
Taking out the rubbish			
Shopping for groceries			
Cleaning the house			
Cooking meals			
Doing the washing			
Making telephone calls for someone else			
Fixing things around the house			
Gardening			
Helping them to get dressed			
Picking things up for them			
Taking them for walks			
Getting them in or out of bed			
Helping with showering or bathing			
Helping them to eat			
Moving them about the house			
Helping with going to the toilet			
Arranging doctors' appointments			
Helping with using transport			
Writing letters or filling in forms			
Talking to doctors or other medical people			
Paying their bills			

8. Are there any things you do that we have not mentioned?

**Part 4: Impacts**

Thinking back about some of the things we talked about earlier, in what ways are you affected by your having to look after someone:

- At school
- At home
- With friends

**Part 5: Support**

1. Does your family get any support to cover the costs of looking after someone?
2. Would you like more support?
3. If there was anything else that could happen which would make your life easier, what would this be?

## Appendix 7: Interview schedule for agency staff

### Part 1: Agency background

1. What is the role/remit of your agency?
2. What is your own role within the agency?
3. What is your experience of working in the area of young carers?

### Part 2: Identifying young carers

4. What mechanisms are being used to identify and contact young carers and how effective are they?
5. What mechanisms should be used to identify young carers?
6. In interviewing young carers, what problems and sensitive issues are likely to arise?

### Part 3: Impact of caring

7. How would you define a 'young carer'?
8. What tasks do young carers perform?
9. What are the positive impacts of caring on the young person?
10. What are the negative impacts of caring on the young person?
11. Are some forms of care age-inappropriate?
12. What is the relationship between caring and poverty?

### Part 4: Supporting young carers

13. Does your organisation provide support to young carers?
14. What forms of provision and support should be provided to young carers?
15. Do you feel young carers have 'a voice'?

## Appendix 8: Information and Consent Forms for Parents/Guardians and for Participants

### Information for Parents/Guardians

#### **Dear Parent/Guardian,**

Your child is being invited to take part in a study on young carers in the Irish population. Before you decide whether or not to let your child participate in the study, we feel that it is important for you to know the purpose of the research and what it involves. This sheet will hopefully answer any questions you might have. If anything remains unclear, please feel free to contact us. If you agree to take part, please sign the attached consent form.

#### *Who is conducting this study?*

The Child and Family Research Centre (CFRC) at the National University of Ireland, Galway is conducting this research with young carers in the Irish population on behalf of the Office of the Minister for Children and Youth Affairs (OMCYA). The people on the research team are Dr. John Canavan, Dr. Allyn Fives, Bernadine Brady, Dr. David Cairns and Danielle Kennan, who are all researchers at the CFRC.

#### *What is this research about and what does it involve?*

The purpose of this research is to look at the impact providing care has upon young carers' lives and to make recommendations to the OMCYA for ways to improve support to them. The study itself involves talking to young carers throughout Ireland about their experiences.

#### *How can you help?*

We are interested to hear about young carers' experiences of providing care and the impact being a carer has upon their lives. We are asking your permission to allow your child to be interviewed as part of the study. Participation is entirely voluntary and a meeting will only take place once both you and your child provide written consent. The meeting itself should take no more than an hour in duration and your child can leave at any time or refuse to reply to any questions they do not want to answer.

#### *How will the information be treated?*

Only members of the research team will have access to your child's responses. We will treat them confidentially. Neither will anything be published from which a participant could be identified. However, the researchers are bound by the *Children First* guidelines. This means that no information about your specific child will be passed on to Government bodies unless the researcher feels there is a significant risk. All information will be securely stored for five years after the completion of the study.

#### *Who can I talk to if I need further advice about participating in the study?*

Danielle Kennan can be contacted at the Child and Family Research Centre at 091 495373 or [danielle.kennan@nuigalway.ie](mailto:danielle.kennan@nuigalway.ie)

If you are willing to allow your child to participate, please return the form to:

Ms. Danielle Kennan  
Child and Family Research Centre  
Science, Engineering & Technology Building, NUI Galway

*Many thanks for your cooperation.*

## Consent Form for Parents/Guardians

1. I have read the attached information about the purpose of this meeting with my child. ☐
2. I fully agree to my child's participation in this meeting. ☐
3. I understand that my child is free to leave the meeting at any time and can refuse to answer any questions should they wish to do so. ☐

Signed: \_\_\_\_\_

Please print name: \_\_\_\_\_

Date: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_

*Thank you for your help.*

## Information for Participants

### Dear Participant,

This letter is to invite you to take part in a study on young carers in the Irish population. Before you decide whether or not to help us, we feel that it is important for you to know the purpose of the research and what it involves. This sheet will hopefully answer any questions you might have, but if anything remains unclear please feel free to contact us. If you agree to take part, please sign the consent form.

### *Who is conducting this study?*

The Child and Family Research Centre (CFRC) at the National University of Ireland, Galway is conducting this research for the Office of the Minister for Children and Youth Affairs (OMCYA). The people on the research team are Dr. John Canavan, Dr. Allyn Fives, Bernadine Brady, Dr. David Cairns and Danielle Kennan, who are all researchers at the CFRC.

### *What is this research about and what does it involve?*

The purpose of this research is to look at the impact providing care has upon young carers' lives and to look for ways to support them. The study itself involves meeting with young carers throughout Ireland.

### *How can you help?*

We are interested to hear about your experiences of providing care and the impact this has upon your life. We are asking your permission for us to talk to you as part of the study. Participation in the study is entirely voluntary and this meeting will only take place once both you and your parent/guardian provide written consent. This meeting should take no more than an hour in duration and you can leave at any time or refuse to reply to questions you do not want to answer.

***How will the information be treated?***

Only members of the research team will have access to your answers and will keep them totally private. No information about you will be passed on to Government bodies unless the researcher feels you are at significant risk. Neither will anything be published from which you could be identified.

***Who can I talk to if I need further advice about participating in the study?***

Danielle Kennan can be contacted at the Child and Family Research Centre at 091 495373 or [danielle.kennan@nuigalway.ie](mailto:danielle.kennan@nuigalway.ie)

If you are willing to participate, please return the form to:

Ms. Danielle Kennan  
Child and Family Research Centre  
Science, Engineering & Technology Building  
NUI Galway

*Many thanks for your cooperation.*

**Consent Form for Participants**

1. I have read the information given to me and I understand the purpose of this meeting. ☐
2. I fully agree to participate in this meeting. ☐
3. I understand that I am free to leave at any time and I can refuse to answer any questions should I wish to do so. ☐

**Signed:** \_\_\_\_\_

**Please print name:** \_\_\_\_\_

**Date:** \_\_\_\_\_

*Thank you for your help.*



## Appendix 9: Distressed Children Protocol

In the original research plan, we have stated that we will not interview children and young people who are likely to be in a state of distress, e.g. those who have suffered a recent bereavement. This does not mean that we will not encounter those in need of assistance. While we know that many children and young people are resilient and able to cope with what may be challenging personal circumstances, we cannot discount the idea that certain individuals may react adversely to discussing their experiences as young carers. It may be the first time someone has discussed this subject with an 'outsider' or a rare occasion in which to discuss such matters, which can have a considerable emotional weight.

As dedicated child, youth and family researchers, we know that it is important that these children and young people do not experience further distress as a result of their participation in the research; likewise, researchers cannot be burdened by what may be for them an inappropriate emotional burden. For these reasons, it may be necessary to make recourse to other parties for assistance in coping with distress. Furthermore, we are also bound by the *Children First* guidelines, which provide specific guidelines for appropriate behaviour when working with children and protocol for circumstances wherein there is evidence of abuse.

In the event of distress arising during the interview, the basic procedure will be to stop the interview and refer the child or young person to someone in a position to help, specifically:

**Parent/Guardian** – Unless the child or young person indicates a preference to the contrary, immediate recourse will be made to a parent/guardian, who will be in the home while the interview is taking place and close at hand. For younger age groups, parents may also be present during the interview.

**Referral to agencies** – For referrals made via agency staff, there is the additional option of contacting the individual who made the referral. This would typically be in cases where the expertise of agency staff (e.g. in relation to a particular illness or disability) would be of relevance. Phone numbers will also be available for various helplines (*as listed below*).

**Referral to Child Protection Officer** – If there are 'reasonable grounds for concern,' e.g. where a child or young person is in a situation of abuse (defined as neglect, emotional abuse, physical abuse or sexual abuse), they will be referred to a Child Protection Officer. In the event of a disclosure of abuse, the *Children First* guidelines will be followed.

Time will also be allocated at the end of each interview for discussion of any sensitive matters that may arise and which the participant may wish to discuss unrecorded. The children and young people are also free to halt the interview at any time and refuse to answer questions they do not wish to respond to.

### Helplines available:

- National Careline Freephone – 1800 240724
- Childline – 1800 666666
- Citizens Information – 1890 777121
- Al-Anon/Alateen – (01) 873 2699
- Solas (bereavement helpline for children – Barnardos) – (01) 473 2110
- Gingerbread Ireland (Lone Parents and Children) – (01) 671 0291
- Aware (non-directive counselling) – 1890 303302
- Samaritans – 1850 609090
- CARI (Children at Risk in Ireland) Foundation Helpline – 1890 924567

## Appendix 10: NVivo Coding

### Coding for young carers' interviews – aged 12-17

Demographics	School	At home	Social activities	Looking after someone at home	Tasks involved	Impact school	Impact home	Impact friends	Support	Any other questions
Age Gender Place of birth Address Family structure Parent's work	What school School history Current level Happy in school Favourite subjects Relationship with teachers Perceptions of teachers	Morning time Bed time Own space TV Like where you live Out on one's own	Number of friends Time with friends Friends visiting Activities Age of friends Own interests	Who needs care Why help is needed Length of time caring Whose idea it was Feelings about it Advice or support	Rubbish Shopping Cleaning Cooking Washing Phone calls Fixing things Gardening Dressing Picking things up Walking Bed help Bathing Eating Mobility Toilet Doctors' appointments Transport Letters Talking to doctors Bills Other	Absences and punctuality Distracted Homework Exams Bullying Extra help Other	Sleep Worry Eating Boredom On call Closeness Maturity Other	Unable to meet friends Holidays Drink or smoke Supportive friends Friends in similar situation Going out Left out Included Other	Support provided Support wanted To make life easier	

### Coding for young carers' interviews – aged 5-11

Demographics	Tasks involved	Social activities	At home	Impact home	Looking after someone at home	Impact school	Any other questions
Age	Cooking	Own interests	Own space	Sleep	Advice or support	Bullying	
Gender	Gardening	Time with friends			Feelings about it	Falling asleep	
Place of birth	Rubbish					Upset	
Address	Washing					Tired	
Family structure	Shopping					Homework	
Parent's work	Phone calls					Teachers	
	Cleaning					Other	
	Vacuuming						
	Meals						
	Transport						
	Doctors' appointments						
	Bed help						
	Bathing						
	Visiting hospital						
	Child minding						
	Reading together						
	Other						

### Coding for agency interviews

Agency background	Identifying young carers	Impact of caring	Supporting young carers	Anything else
Remit of agency	Mechanisms being used	Definition	Your organisation	
Role within agency	Mechanisms that should be used	Tasks	Support that should be provided	
Experience of young carers	Problems interviewing young carers	Positive impacts	Voice	
		Negative impacts – emotional		
		Negative impacts – education, social		
		Negative impacts – other		
		Age-inappropriate		
		Caring and poverty		

## Appendix 11: Geographical distribution of participants by county

County	No. of young carers (n = 26)
Carlow	1
Cork	1
Dublin	4
Galway	11
Kilkenny	1
Leitrim	2
Meath	1
Sligo	4
Tipperary	1



Oifig an Aire Leanaí  
agus Gnóthaí Óige  
Office of the Minister for  
Children and Youth Affairs



**An Roinn Sláinte  
agus Leanaí**  
DEPARTMENT OF HEALTH AND CHILDREN

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Web: [www.omcya.ie](http://www.omcya.ie)