



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



# Study of Young Carers in the Irish Population

## EXECUTIVE SUMMARY

The National Children’s  
Strategy Research Series



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# Executive Summary

## Background to the study on young carers in the Irish population

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. Traditionally, the focus of carer-orientated policy has been on adult carers. However, in the past 15 years there has been growing awareness of and interest in young carers. A number of key issues have emerged in the literature on young carers:

- the definition of a young carer;
- the impacts, both positive and negative, of caring on a child or 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.

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 (OMCYA, 2008). The Government's approach was two-fold: (1) it requested the Central Statistics Office to undertake additional analysis on the 15-17 year-old children identified in the Census as carers and (2) it commissioned this research study through the Office of the Minister for Children and Youth Affairs (OMCYA).

The specified aims of this research were to examine mechanisms through which young carers (aged 5-17 years) in the Irish population can be identified, to investigate the impact of caring on their lives and to make recommendations for ways in which they can be assisted.

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.

## Overview of national and international literature, policy and law

Providing care in the home is something most, if not all, children are encouraged to do. However, there is a 'continuum of caring' within families and young carers are at one extreme of this continuum in terms of the tasks they perform and the impact of these tasks upon their lives (Frank, 2002). A young carer need not be the main or primary carer in the home: many young people's lives are significantly affected by the 'support' they give to an adult carer.

Building on the work of Frank (2002), Gray *et al* (2008) and Thomas *et al* (2003), the research team for this study proceeded with the following working definition of 'young carer':

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 take on a variety of caring tasks, as studies in the UK in particular have found (Dearden and Becker, 2004, p. 7). The tasks include domestic help, general help (help with medication, mobility or feeding), emotional support, intimate care (help with toileting, bathing or dressing) and childcare (looking after siblings). The health problems of those with care needs vary as well: some have problems with physical health and others with mental health, others have intellectual and/or physical disabilities, and some suffer from sensory impairments or an alcohol or drug addiction.

Young carers themselves, their parents and service providers may not necessarily like or even accept the label 'young carer' since it can imply a stigma. Some families, in contrast, see caring as a normal part of family life and for that reason do not believe that the term 'young carer' is appropriate. Moreover, even professionals can be unwilling to use the term. Some professionals may view it as part of normal family life, while others may fear that the only service response available to a young carer is a child protection intervention (Gray *et al*, 2008; Roche and Tucker, 2003). The 'hidden' or 'covert' nature of care thus has important implications for any attempt to recruit young carers for research purposes.

Caring need not be a completely negative experience for a young carer. Caring may lead to greater maturity, closeness to the person cared for and compassion. Nonetheless, the potential negative impacts of caring have attracted a great deal of attention in the areas of education, social life, emotions and physical health. The provision of intimate care is sometimes categorised as 'age-inappropriate' care. The same is the case for the status of primary carer, i.e. the main or predominant carer in the household. The fear is that there is a danger of 'parentification' or role reversal between parent and child (Earley and Cushway, 2002; Hooper, 2007).

Research on young carers has recently been challenged on a number of fronts. For some, there is a tension between a children's rights approach and 'the rights-based approach of the disability movement, with its emphasis on the needs and rights of disabled people as parents' (Aldridge, 2008, p. 254). According to the former position (*see* Newman, 2002; Olsen, 2000; Parker and Clarke, 2002; Parker and Olsen, 1995), studies on young carers exaggerate the numbers of carers; over-estimate the numbers of primary carers; do not properly acknowledge the difficulties of ascribing particular effects to caring as a child; and imply that ill or disabled parents either selfishly prioritise their interests over those of their children or lack the ability to parent. However, those researching young carers have responded, pointing out that there need be no conflict of interests between young carers and their ill or disabled parents (Aldridge, 2008). Also, research on young carers is subject to the same requirements of rigour and objectivity as social research in any other area.

There is no national legislation that specifically protects the rights and welfare of young carers in Ireland. Nor are there services or policies specifically for young carers. The relevant international human rights framework is the United Nations Convention on the Rights of the Child (UN, 1989). Articles in the Convention relevant to young carers include the best interests of the child principle



(Article 3), the right of the child to express their views on matters that affect them (Article 12), the right to the enjoyment of the highest attainable standard of health (Article 24), and rights to education (Article 28), to leisure (Article 31) and to freedom from exploitative or dangerous work (Article 32).

As is the case elsewhere, it is difficult to calculate the prevalence of young carers in Ireland. This is due, in part, to the invisible nature of their role within society. Statistics from the 2006 Census provide some indication of possible levels of young people aged 15 and older providing care (CSO, 2007): in 2006, 3,166 carers between the ages of 15 and 17 were identified, accounting for approximately 2% of the population in this age category (n = 171,585). Of these young carers, 81% (n = 2,561) reported providing between 1-14 hours unpaid work per week; 8% (n = 254) provided between 15-28 hours of care per week; 4% (n = 131) provided 29-42 hours of care per week; and 7% (n = 220) reported providing more than 43 hours of care per week.<sup>1</sup>

While 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>2</sup>

In sum, the literature on young carers emphasizes that this is an invisible or hard-to-reach group. The invisibility of young carers is of particular relevance in the Irish context given that there are no services, policies or laws specifically for them and this is of central significance for any attempt to identify and recruit young carers as research participants. The literature also indicates that there is a broad spectrum of caring situations, with young carers taking on different levels of responsibility, performing different care tasks, responding to a variety of care needs and enjoying varied levels and types of assistance and support. A more detailed examination of the literature is available in the *Main Report* for this study (Fives *et al*, forthcoming).

## Methodology

To meet the objectives of the research, the study undertook empirical work with 26 young carers and 30 agency staff in the statutory and non-statutory sectors.

There were two different phases of recruitment of young carers in this study. Phase 1, by and large, was not successful. A nationwide information campaign, which involved the distribution of posters and flyers to all post-primary schools (approximately 760 across Ireland) and to a wide range of youth organisations, did not generate a single referral. However, in this phase, agency staff referred 6 young carers to the study. Phase 2 of recruitment was a vast improvement. The research team established personal relationships with front-line staff, had repeated and lengthy telephone conversations explaining the research and its implications for young carers, and successfully recruited agency staff to act as 'gatekeepers' for the research team. This included 15 different gatekeepers from agencies in the statutory and non-statutory sectors, all working in the area of children and families. As a result, a total sample size of 26 young carers was reached. However, the original objective was to conduct interviews with 30 young carers; despite exhausting all avenues, this aim was not achieved.

The lack of success in Phase 1 of the recruitment process was a crucial finding. It showed that agency staff were unwilling to respond to written requests for referrals and instead referrals would be generated only on the basis of the research team's personal relationships with gatekeepers.

<sup>1</sup> Additional data provided by the CSO at the request of the OMCYA.

<sup>2</sup> Additional data provided by the CSO and made available by the Carers Association.

This reflects the sensitivity of this area and in consequence the fact that young carers are to an important extent 'invisible'. Indeed, use of the term 'young carer' was itself an obstacle to recruitment due to the lack of awareness. Other researchers who relied on written requests for referrals also failed to recruit a sufficient sample (Thomas *et al*, 2003). Nonetheless, in the UK, young carers have come forward and joined 'young carers projects' and also taken part in young carers surveys. This may be because there has been a concerted effort over the last 15 years to establish bodies that represent the interests of and provide services to young carers, and which adopt child- and youth-friendly approaches, including the use of web-based resources (Dearden and Becker, 2004; Roche and Tucker, 2003).

To meet the objectives of the present research, empirical work was also undertaken with 30 agency staff. Agency staff were recruited from various parts of the country from the statutory and non-statutory sectors. The sample included front-line staff, managers, researchers and policy-makers, and the sample was drawn from agencies or Government departments with responsibilities for carers, child and youth work, social work, family welfare conference coordination, disability and mental health. Many of the agency workers recruited to take part in interviews also played a role in the recruitment of young carers. The purpose of the interviews was to learn directly from agency staff about their experiences of working with young carers.

The recruitment and interview process in relation to both the young carers and the agency staff was conducted according to strict ethical guidelines. Written consent was sought and obtained from parents and all participating young carers, and ethical approval was received from the NUI Galway Research Ethics Committee.

With regard to methodological limitations, the research team failed to recruit and interview children and young people of parents with drug and alcohol addictions. It is, therefore, likely that the final sample does not include the most vulnerable categories of young carers. Given that the young participants were recruited on the basis of their parent's or guardian's consent, however, it was thought that the parents of vulnerable children would be less likely to volunteer information about their family life or to encourage outside interest in their family.

## Findings from interviews with young carers

Each participating young carer was given an identification number and letter, ranging from P1 to P26. Quotes from participants are given throughout this report; they have been subjected to minimal editing in order to retain the tenor of the comments made.

### Profile

Interviews were conducted with 26 young carers, 7 of whom were male and 19 female. Of these, 11 participants lived in rural areas and 15 in urban areas; 10 participants were aged 5-11, while 16 were aged 12-18. The average age of participants was 13.29 years.

As Table 1 shows, 15 of the participants were caring exclusively for a sibling(s) and 7 were caring exclusively for a parent(s). Except for one young carer providing care for both parents, all those caring exclusively for a parent(s) lived in a single-parent household, 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 (in one of these families, siblings were also in receipt of care). A total of 7 young carers lived in households that contained two adults in paid work, and in all cases save one, the young carers were caring exclusively for siblings. The exception was a household where a grandmother was cared for by her grandchildren, two young sisters.

**Table 1: Association between household structure and person(s) cared for (n = 26)**

Person cared for	Young carers in single-parent family	Young carers in two-parent family	Total
Mother only	5	0	5
Father only	1	0	1
Both parents	0	1	1
Sibling(s) only	0	15	15
Grandparent	2	0	2
Sibling(s) and parent	2	0	2
Total	10	16	26

As Table 2 shows, the majority of participants had been caring from below the age of 5 (n = 14). Many reported 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 responsibilities low.

**Table 2: Age at which caring began (n = 26)**

Age caring began	Young carers
Below 5 years	14
5 – 8 years	5
9 –12 years	5
13 – 15 years	1
16 years and older	1
Total	26

The experiences of the young carers interviewed varied, in particular with regard to the clinical condition of the person in receipt of care. Of the 28 people in receipt of care, 13 had an intellectual disability; 6 had a combined intellectual and physical disability; 5 had a physical illness; 3 had a mental illness; and one had a sensory impairment. Young carers also differed in terms of the level of their responsibilities towards the person cared for: 9 of the young carers were primary carers (mostly caring for a parent), while 17 were secondary carers (mostly caring for another sibling).

## Supports

Of the supports that young carers reported receiving, the most common was home help. This was followed by peer support, income support for the family, medical treatment for the person cared for, respite care, support from teachers, advice and information, transport and money for home renovations. Young carers wanted to receive more of these supports, in particular home help, respite care, peer support and support from teachers.

One 14-year-old, who cared for her mother with a physical illness, described how gaps sometimes appeared in their home help service and that such shortfalls would happen without warning. Since her mother needed constant care all day long, the young carer reported that when she was at school she would worry about whether her mother had been left alone and uncared for:

*'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.'* (P9)

Friends were another source of support for young carers. Even those young carers who had friends they could rely on also identified friends that were not supportive or not understanding. This was the case with a 10-year-old girl caring for her sister with intellectual disabilities:

'One of my friends, hate. 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. And one of them said, "Only bring me over when she is in respite". I said, "Right, OK"' (P20)

### Tasks young carers perform

The young carers in this study provided numerous kinds of care. While all reported performing domestic tasks, 19 reported providing general care, 17 were providing childcare, 16 provided intimate care, 7 provided emotional support and 7 provided various other kinds of support. Both male and female young carers provided intimate care: in some cases, they provided intimate care to a parent(s) and girls provided it to brothers.

A 14-year-old caring for her mother with a physical illness had considerable responsibilities in this area. She would help lift her mother in the bathroom, both in the home and in public toilets. However, she was not eager to continue providing intimate care:

'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.' (P9)

### Impacts of caring on young carers

The young carers were asked about the impacts that providing care had in various areas of their lives. In most cases, they felt that there were both positive and negative impacts. For example, while some young carers were doing well in school, others were distracted and worried when at school or else absent from school whenever there were crises at home (P16). Although many had the time and resources to socialise with friends, join clubs and take part in sports and extra curricular activities, for others, caring was a restriction on their social life. In one case, a young carer reported feeling bored when away from school:

'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.' (P21)

Nearly all reported feeling more mature than their peers. Greater maturity often meant greater awareness of issues relating to illness and disability, or greater responsibilities. However, some did not welcome what they saw as adult responsibilities:

'Well, I had to deal with an adult situation when I was 8 years old!' (P9)

Concerning emotional impacts, one young carer spoke of being happy to help his brothers (P19) and another of how happy her brother was despite his illness (P23). In some cases, however, carers worried about the future care needs of the person cared for:

'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 [her brother] would be like in about 20 years or so. I just thought it might upset me.' (P22)

The negative physical impacts of caring included symptoms such as back strain caused by lifting an adult. This was the case for a 14-year-old who talked about the physical effects of lifting her mother. A further impact of caring on carers concerned poverty and socio-economic disadvantage. A number of families were totally dependent on whatever income support they were entitled to receive from the State.

### Impacts on primary carers

Primary carers deserve special consideration because they take on a higher level of responsibility. A teenage girl, caring for her father and siblings, said she was glad to help:

‘Yeah, because you learn so much responsibility, and everything, for when you’re older.’  
(P15)

Nonetheless, despite her positive feelings about her role, she said that if there was a crisis in the household, she would leave school straight away to address the problem herself: ‘School would be the last thing,’ she said. Therefore, the burden of being a primary carer may have significant consequences for this young girl’s education and future opportunities.

### Impacts of providing intimate and/or general care

Twenty-one of the young carers were providing intimate and/or general care. One of this group, a 16-year-old boy, reported that he sometimes felt stressed at school and sometimes had no time for his friends and his various interests. Nonetheless, he said:

‘I personally feel that if I can make their life a little easier, then I’m happy, do you know ... I just feel that I am their bigger brother so I should help, you know.’ (P19)

Others, in contrast, felt 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 would not explain what was happening to their lives, and they did not get help from peers, teachers, youth organisations or health professionals. Some also felt that they never got a break from caring – they were always ‘on call’.

### Gender and care

There was a gendered dimension to caring (see Table 3). In some families, boys took on considerable caring responsibilities and often did so without expressing reluctance. However, in other households care tasks were taken up by female relatives, even when other male siblings were available and able to help. One young carer stressed that her responsibilities as a carer were very different from the responsibilities of her brothers because her brothers got to decide first when they would be away from the home:

‘The lads decide where they go first ... I’d probably do it [the caring task] just to avoid the argument, like.’ (P9)

**Table 3: Association between gender and level of responsibility (n = 26)**

Gender	Primary carer	Secondary carer
Male	3	4
Female	6	13
Total	9	17

### Findings from interviews with agency staff

Besides young carers, interviews for the present study were also conducted with 30 agency staff in both statutory and non-statutory agencies, all working in the area of children and families. Reflecting the absence of any legislation, policy or service in Ireland specifically for young carers, none of the agency staff interviewed had professional contact with young carers on anything but an ad hoc basis.

## Definition

The participating agency staff were asked to define young carers. Almost half of them (14) used the term 'young carer' to refer exclusively to those engaged in 'inappropriate care'. Some of this group believed that young people providing care is by definition inappropriate, while for others a situation merited being referred to as one of 'caring' only if it raised child protection concerns. In contrast, 16 of the participants believed that there is a continuum of caring and that some caring is positive. Although in some cases caring is problematic and raises child protection concerns, they contended that it is important to distinguish caring from 'risk' and 'vulnerability'. Also, if caring is mediated correctly, it can have positive impacts and the policy and service response should acknowledge the distinction.

## Identification of young carers

Seven of the agency staff interviewed were able to refer young carers to the study. However, a further 14 participants were unable to generate referrals: 7 of them tried and failed, while 7 felt unable to do so.

It was agreed that the identification of young carers would be difficult since the issue, according to agency workers themselves, was '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. It was noted that at present professionals working in State agencies do not record data on young carers when delivering services to a family.

## Gaps in knowledge

Significant gaps in professional knowledge about young carers emerged from the interviews. Some of the agency staff – including those who had referred young carers to the study – were unaware of the prevalence of young carers, their provision of intimate care, the age at which they began caring, the primary status of some of them and/or the lack of support from and awareness of school teachers. This knowledge deficit is due to agency staff only having contact with young carers on an ad hoc basis; indeed, participating agency staff themselves believed the issue was 'under the radar' and they called for a budget to be set aside for young carers.

## Discussion

This study has uncovered the reality of caring by children and young people in the Irish population. Some of the children and young people are primary carers, others are helping to provide care. Caring begins at a very young age and in many cases 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,' negative impacts can be serious and require a concerted response in terms of policy, legislation and service provision.

Uncovering the reality of caring is all the more important because young carers are to a great extent 'invisible'. 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 pathological welfare category.

## Defining young carers

Some have suggested that the term 'young carer' is itself problematic since it exaggerates the negative impacts of caring and also undermines the interests of parents, in particular parents with a disability or illness (Olsen, 2000; Parker and Clarke, 2002; Parker and Olsen, 1995). It is the case that 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, the social categories we use imply a social stigma (Goffman, 1963). However, the findings in this study from the interviews with young carers provide good reasons to accept the reality of the phenomenon of children and young people caring. It is a separate issue then to ensure that using the term 'young carer' will not imply a stigma.

## Identifying and accessing young carers

One consistent finding from the literature is the ‘invisibility’ of young carers and so identifying and gaining access to young carers is also a problem (Thomas *et al*, 2003; Banks *et al*, 2002a and 2002b; Aldridge and Becker, 2003). The gaps in knowledge concerning young carers also suggest that professional knowledge of, and training in, the area of young carers should be addressed.

Any attempts to gain access to young carers in Ireland would have to replicate the methods adopted in this study and collaborate with agency staff (gatekeepers) over a lengthy period. Young carers did not self-refer to this study. However, in the UK young carers have themselves sought support from ‘young carers projects’ and researchers have accessed young carers through such organisations (Dearden and Becker, 2004). Similar organisations could be beneficial elsewhere. Moreover, there is no legal obstacle to a person below the age of 18 being placed on a HSE database of ‘informal carers’ in Ireland, which could help raise awareness about young carers and facilitate accessing them.

## Impacts of caring on young carers

The findings from interviews with young carers in this study show that the impacts of caring are not always negative and that since many young carers are happy to provide care, they would continue to do so even if service provision were better. Nonetheless, it may be that some young carers are asked to do too much too young. In such situations, there is a legitimate fear of ‘over-functioning’ (Halpenny and Gilligan, 2004). Interviews with young carers suggest two very different scenarios to illustrate the positive and negative impacts of caring (*see below*).

### 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

The evidence from this study suggests that the best way to support young carers, and thereby ensure their rights, is to examine ways in which to raise awareness about young carers, while encouraging both formal and informal supports.

Formal services, such as home help and respite care, lessen the burden of the carer in the home, without removing the need for this informal caring role. At the same time, young carers themselves benefit from informal supports, in particular from friends, family and community groups. The theory of 'family support' suggests that informal networks provide not only concrete forms of support, but also emotional support, advice and guidance. At the same time, the concept of family support must allow a critical perspective to be taken on the 'concrete awfulness' that some children and parents face (Canavan, 2008, p. 4). It is fair to say that some of the young carers in this study could not function properly without the formal services they receive, but also it is clear that they do not receive enough of these. However, it does not follow that such families do not need informal supports as well.

The invisibility of young carers was borne out by the difficulties experienced in recruiting participants to this study, but the study also illustrates that, with the cooperation of a variety of gatekeepers, it is possible to identify young carers. Interviews with young carers and also agency staff support the view that there is a continuum of caring, running from caring situations that are age-inappropriate, at one extreme, to situations where the caring role is largely positive, at the other. As a result, the levels and types of supports required by young carers vary. Finally, this study has found that the situation of young carers is improved when there are both formal and informal supports available and when there is greater awareness of the caring role, and as a result better protection of children's rights.

### 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 section 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. 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 studies, including Dearden and Becker's survey of over 6,000 young carers in the UK (Dearden and Becker, 2004), and the definition used in this study builds on those employed by Gray *et al* (2008), Frank (2002) and Thomas *et al* (2003).

The health problems of those with care needs were recorded as well and they included:

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

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

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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 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 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 young carers 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 young carers.
- 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 sport 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 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 taking part in interviews 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 school teacher or Principal, a friend, a professional helping the person in need of care in the home or someone from a carer 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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