

A Study of Young Carers in the Irish Population

BRIEFING NOTE

What is the purpose of this study?

The purpose of this independently peer-reviewed study was to examine mechanisms through which young carers in Ireland can be identified, to investigate the impact of caring on their lives and to examine ways in which they can be assisted. This briefing note summarises the methodology, key findings and conclusions of the study. A more detailed report can be downloaded at www.omc.gov.ie.

How was the study undertaken?

This study involved a review of the national and international literature, together with a number of interviews with young carers and agency staff.

The literature on young carers emphasizes that this is an 'invisible' or hard-to-reach group – a finding of particular relevance in the Irish context given that there are no services, policies or laws catering specifically for them. 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.

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.



What are the key findings?

What is a young carer?

Interviews with young carers in this study uncovered a continuum of caring and, taking their views into account, the following definition is suggested:

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.

What tasks and responsibilities are involved?

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.

The health problems of those with care needs were also recorded and these included:

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

Young carers in this study identified different levels of responsibility, 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.



In this study, 9 of the participants were primary carers and 17 were secondary carers. All primary carers cared for a parent and all secondary carers cared for a sibling. In two cases, the young people cared for both their parents *and* their siblings, and two young sisters provided care for their grandmother.

What are the impacts for young carers?

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 distracted while 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 and other stakeholders included:

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



What supports were received?

Young carers in this study reported on the supports they received, as well as supports for the person with the care need or their family. These included:

- home help;
- respite care;
- advice and information;
- support from friends and family members;
- support from teachers and school principals;
- better treatment for the person with the care need;
- help with transport and home renovations.

The young carers also reported that they wanted – and needed – more of these supports.

What are the conclusions for POLICY in this area?

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.

1. Coordinated cross-sectoral, multidepartmental and multiagency approach

The findings from the study show that young carers not only need more formal support but also that they would benefit from a variety of services. Therefore, young carers can be best supported by adopting a cross-sectoral, multidepartmental and multiagency approach. A successful initiative in developing and implementing policy and services in a similarly complex area has been to create a working group that includes stakeholders from the statutory and non-statutory sectors – see the *Report of the Working Group on Elder Abuse* (Department of Health and Children, 2002). The establishment of Children’s Services Committees in the 10-year Framework Social Partnership Agreement 2006-2015, *Towards 2016* (Department of the Taoiseach, 2006) and the development of the new National Children’s Strategy (forthcoming, OMCYA) may also provide a mechanism through which this issue can be addressed. In addition, developing a new focus on young carers would require a re-examination of existing budgets in these agencies and departments.



2. 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 and to an important extent ‘invisible’. 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 term, but also awareness needs to be raised among parents/guardians and professionals.
- Many agency staff participating in the study felt it would be unfair to raise awareness about young carers without also providing services designed for them.

3. Ensuring children and young people have a voice

As part of a rights-based approach, any developments in policy and services relating to young carers should ensure that the voices of young carers are heard and taken into account.

4. Recognising the continuum of care and diversity of supports required

The continuum of caring identified in this study suggests that any response to young carers should acknowledge the variety of caring situations and the diversity of supports needed.

5. Improved understanding of children as carers

Greater knowledge is needed about the number of young carers in the Irish population. This could be facilitated if Census data were collected on young carers below the age of 15, as is the case currently in the UK. 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.

What are the conclusions for SERVICES in this area?

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.

1. The needs of young carers

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.

Agency staff interviewed for this study believed that young carers may have behavioural or psychological problems if their caring role is not properly managed. Research from the UK shows that, by and large, despite extensive legislation and policy specifically for young carers in that country, services only intervened to respond to the needs of young carers when there was a child protection concern.

2. Create mechanisms for young carers to contact service providers

It is essential that young carers are recognised and encouraged to come forward to relevant organisations so that their needs can be addressed. Relevant in this context are the 'young carers projects' in the UK, which encourage self-referrals from young carers by establishing dedicated websites and organisations (e.g. the Princess Royal Trust for Carers, www.youngcarers.net).

Other mechanisms can include:

- a targeted information campaign in primary and secondary schools;
- increase the profile of potential caring responsibilities of young people among professionals;
- identify and raise awareness about the characteristics of young carers, including such indicators as absence from school, distracted while at school, unavailable for extra-curricular activities or suffering from illness or injury as a result of their caring role.



3. Proactively identify young carers where there is a known care need

A proactive approach should be taken to seeking out and identifying young carers in households where there is a known care need. Also, the remit of existing organisations that already provide services or that are in contact with people who have caring needs could be extended where appropriate. Finally, 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.

4. Develop referral pathways to supports

It is important for any service providers in contact 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.

5. 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 young carers, the care provided and the recipients of care;
- encourage young people to come forward and let someone know about their caring role: a teacher, a friend, a professional helping the person in need of care in the home or someone from a carer organisation or youth organisation;
- encourage young carers to actively seek out supports, whether they are informal or formal;
- identify potential areas of need, including information 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.

What are the benefits of this study?

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. It is of particular significance that the voice of young carers has been heard in this study. It represents, therefore, an important starting point for policy, services and research in this area in Ireland.



- ✓ For more research from the Children's Funded Research Programme, see www.omc.gov.ie
- ✓ For more information on children, see www.childrensdatabase.ie