

# Engaging with Young Carers: A Virtuous Circle



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# What Is EPYC?



The Empowering Professionals to support Young Carers (EPYC) project began in August 2016 with six partners from five countries coming together to share knowledge and experience in developing strategies to help professionals working with young people to identify, understand and better support young carers. The project targets youth workers and education, health and social care professionals in Austria, Germany, Ireland, Italy and Scotland who work with and around young people, some of whom may be young carers. Awareness-raising tools such as posters, flyers, web resources and videos have been shared and collated in an online database (available at [www.ep-yc.org](http://www.ep-yc.org)). The eventual desired outcomes of the project are increased knowledge and competence among practitioners in identifying young carers, and increased knowledge and understanding of the particular challenges they face. The multinational project was designed to develop and share innovative practices and to promote co-operation, and was awarded funding under the Erasmus+ youth programme. The project timeline was August 2016 to July 2018.

## Who Are Young Carers?

Young carers and young adult carers are people between the ages of 13 and 25 who are providing care for a parent, sibling, friend or other close relation who has an illness or disability, which may include mental illness or a problem with substance misuse. Young carers provide support in their family by taking on extra, usually adult, responsibilities, including dispensing medication, feeding, personal care, dressing, or making sure bills have been paid. The level of care provided varies depending on the family situation and the needs of the person being cared for. Young carers may also help the family in other ways, like looking after brothers and sisters, shopping for food, doing extra washing, or preparing dinner.

Young carers have been identified as a group at risk of social exclusion; additional health problems, including mental health difficulties; and curtailed opportunities in progressing through education and the workplace.

In 2013, Saul Becker<sup>1</sup>, a thought leader in the area and long-time advocate for young carers, conducted an online survey of 295 young

<sup>1</sup> Sempik, J and Becker, S (2013) *Young Adult Carers at School: Experiences and Perceptions of Caring and Education* (London: Carers Trust); Sempik, J and Becker, S (2014) *Young Adult Carers and Employment* (London: Carers Trust).

people aged 14–25 years with additional caring responsibilities. The study found that over three-quarters of the respondents were female. Overall, they reported ‘very high’ levels of caring, and while they felt their health was ‘good’, their mental health was less robust.

Eurocarers, the European association working for carers, suggests that

 **Young carers across Europe carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. Although there are no precise figures about how many young carers there are across Europe today, data suggests that about 7–8% of children in Europe will have caregiving responsibilities. These are children who are largely invisible to public authorities, social policy and interventions from health and social care services.<sup>2</sup>**

This could mean that 6 million children across Europe are providing family care but not receiving the support they need.<sup>3</sup>

In Ireland, we may have an even higher incidence of young carers than the European figures suggest. The 2014 HBSC School Survey (Ireland)<sup>4</sup> included a question on caring responsibilities, and reported that 56,118 young people aged 10–17 (11.3%) are providing care across Ireland. This is a multiple of the figure reported in the Census 2016 data<sup>5</sup>.

56,118 young people aged 10–17 (11.3%) are providing care across Ireland.

<sup>2</sup> Eurocarers Policy Paper: Young Carers

[www.eurocarers.org/userfiles/files/Eurocarers%20Policy%20paper%20Young%20Carers.pdf](http://www.eurocarers.org/userfiles/files/Eurocarers%20Policy%20paper%20Young%20Carers.pdf)

<sup>3</sup> Eurostat estimates EU population at 511.8m at 1/1/2017 and a population of young people under 15 as 15.6% of that population <http://ec.europa.eu/eurostat/documents/2995521/8102195/3-10072017-AP-EN.pdf/a61ce1ca-1efd-41df-86a2-bb495daabdab>

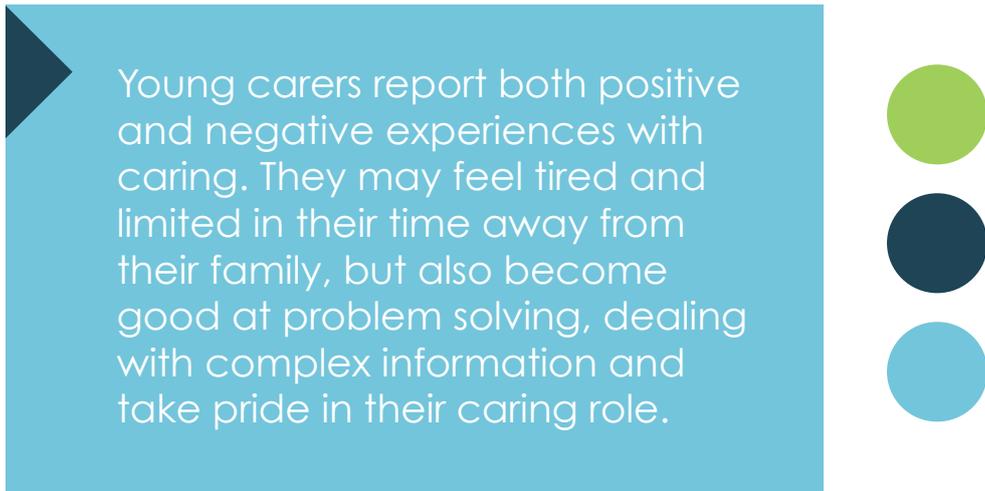
<http://ec.europa.eu/eurostat/statistics-explained>

<sup>4</sup> Gavin, A, Keane, E, Callaghan, M, Molcho, M, Kelly, C, and Nic Gabhainn, S: The Irish Health Behaviour in School-aged Children (HBSC) Study 2014, Health Promotion Research Centre, National University of Ireland, Galway, December 2015.

<sup>5</sup> Census 2016 reports 1.9% of all carers, 3,800 children, as being aged under 15 years:

[www.cso.ie/en/releasesandpublications/ep/p-cp9hdc/p8hdc/p9cr/](http://www.cso.ie/en/releasesandpublications/ep/p-cp9hdc/p8hdc/p9cr/)

The disparity in figures for young carers may be understood through the work of Smail (2007), who suggested they are one of the groups of 'hard-to-reach' young people. There can be many reasons for groups being hard to reach in relation to participation in and with services that allow them to have a voice in the policies and services that affect their lives<sup>6</sup>. For young carers these reasons may include being too tired from their additional responsibilities, or simply not having time to contribute when respite is not available.



Young carers report both positive and negative experiences with caring. They may feel tired and limited in their time away from their family, but also become good at problem solving, dealing with complex information and take pride in their caring role.

There are positive aspects to young people providing family care. They report feeling able to cope with responsibility and like being able to provide support for their family. They may also become good at problem solving, understanding complex ideas and dealing with a range of professional support services. Many take pride in the support they provide for their loved ones, and this is a valuable tool in building their self-esteem. Unfortunately, however, the additional load may limit the young person's opportunity to live a 'normal' teen life, and many are fearful of stigma or of feeling different to their peers. The young carer is also often limited in accessing social and other supports and services outside the home or school, e.g. youth clubs; college and university societies; and sporting, community or other social opportunities. Caring duties can also interfere with school and college work and may hamper progression to further education and employment. Family care tends to be on a spectrum – however, family involvement and responsibilities on a daily basis can turn into a dependence on a young person to the detriment of their own personal, social, educational and even health needs.

<sup>6</sup> [www.cso.ie/en/releasesandpublications/ep/p-cp9hdc/p8hdc/p9cr/](http://www.cso.ie/en/releasesandpublications/ep/p-cp9hdc/p8hdc/p9cr/)

Kelleher, C, Seymour, M and Halpenny, AM (2014) Promoting the Participation of Seldom Heard Young People: A Review of the Literature on Best Practice Principles.

# Literature and Policy in an Irish Context



We now look at some of the policy and literature around young carers, relating it to the Irish context.

The United Nations Convention on the Rights of the Child notes in Article 12 that



*the child who is capable of forming his or her own views [has] the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.*<sup>7</sup>



In 2015, the Department of Children and Youth Affairs (DCYA) published the Government's ***National Strategy on Children and Young People's Participation in Decision-Making, 2015–2020***. This marked the first occasion in Europe where such a policy was published by a national government<sup>8</sup>. The Strategy aims to 'ensure that children and young people have a voice in their individual and collective everyday lives' (p V). The Strategy was to be supported and given an implementation framework through the parallel report ***Better Outcomes Brighter Futures, The National Policy Framework for Children & Young People 2014–2020***, published by the same department in 2014. The aspiration in this document is stated to be that:



*children and young people have a voice and influence in all decisions affecting them (p 4)*

Unfortunately, this contrasts sharply with the current assertion that young carers are under-recognised and not significantly involved in the policies and supports that are available to them, with the 2015 Strategy noting that:



*Despite the developments in improving opportunities for participation by children and young people in decision-making, many of us are aware that there is evidence of Ireland failing to give an adequate voice to children on certain aspects of their lives (p V)*



<sup>7</sup> <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>

<sup>8</sup> Department of Children and Youth Affairs (2015) National Strategy on Children and Young People's Participation in Decision-making, 2015–2020. Dublin: Government Publications. Available at: [www.dcyia.ie](http://www.dcyia.ie)

Section three of **Better Outcomes Brighter Futures** (BOBF) centres on listening to and involving children and young people (p 31). In this section, the report acknowledges the 'importance of children and young people having a voice in decisions that affect their lives regarding the health and social services delivered to them' and that 'seldom-heard' young people are harder to reach and to engage in such processes. Smail recognises young carers as part of such 'seldom-heard' or 'hard-to-reach' groups. The invisibility of young carers is also reflected in the differences in the reporting of numbers of young carers between the Census 2016<sup>9</sup> figures and the HBSC 2014 figures. It is of note that in the latter, children were reporting their experiences directly. Where young people are not seen to need help, it is difficult to develop supports for them.

In a 2007 article, Jean Spence noted that youth workers are one of the primary contacts between policy makers and young people and that 'governments look towards youth work as one possible means of engaging young people who are resistant to, or excluded by, other more formal institutional interventions'<sup>10</sup>. Unfortunately, limited budgets have not allowed for significant engagement of youth workers with policy makers in many areas.

The DCYA strategy on decision-making invokes the use of the Lundy Model of Participation. This stated

-  ***non-hierarchical models of participation emerged as most effective not only because they value all forms of participation, but also because they highlight the importance of the impact and outcomes of participation. The present strategy is underpinned by Lundy's Model of Participation, which is grounded in the UNCRC and focused on a rights-based approach to involving children in decision-making. (p 21)***
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This echoes the 2012 Access All Areas report by the National Youth Council, which suggested:

-  ***Young carers stress the need to be listened to, to be taken seriously and included in any care planning and decisions being made both for themselves and the person they care for. Many speak about the anxiety and frustration they feel from being ignored. (p 12)***
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<sup>9</sup> Census 2016 reports 1.9% of all carers – 3,800 children – as being aged under 15 years.

<sup>10</sup> Spence, J. What Do Youth Workers Do? Communicating Youth Work. Youth Studies Ireland, Vol 2, No 2. Available at [http://youthworkireland.ie/images/uploads/general/What\\_Do\\_Youth\\_Workers\\_Do.pdf](http://youthworkireland.ie/images/uploads/general/What_Do_Youth_Workers_Do.pdf)

Young carers stress the need to be listened to, to be taken seriously and included in any care planning and decisions being made both for themselves and the person they care for.

As part of its remit in promoting and increasing the involvement of young people in policy development, the DCYA has created Hub Na nÓg, a national centre of excellence and co-ordination which supports government departments, state agencies and non-government organisations to give children and young people a voice in decision-making on issues that affect their lives. There is a particular focus on those

who are seldom heard<sup>11</sup>. Contributions and submissions are made by representatives of Comhairle na nÓg<sup>12</sup> and Dáil na nÓg<sup>13</sup>.

The **National Carers' Strategy (2012)**<sup>14</sup> stated that 'in recent years, increased attention has focussed on children and young people who care for a family member. This role can have adverse impacts on their social, educational, emotional and health needs, and on their future life opportunities' (p 6), and that 'the particular situation of children and young people with caring responsibilities was also highlighted as an area that required specific attention' (p 7). Professionals and youth workers who are on the periphery of a young person's caring role are vital in identifying young carers and helping them to access and benefit from support.

Further commitments to young carers were offered in the **National Youth Strategy 2015–2020**<sup>15</sup>, which was published in 2015. This document, which focusses on 10–24 year olds, commits to progressing the following actions over 2015–2017: 'Raise awareness and understanding among education, health and youth service providers of the signs that young people have caring responsibilities, and the impact of caring on them in relation to their education, health and recreation pursuits.' Objective 2.2 of the National Carers' Strategy specifies the need to 'support children and young people with caring responsibilities and protect them from adverse impacts of caring responsibilities'.

<sup>11</sup> [www.hubnanog.ie](http://www.hubnanog.ie)

<sup>12</sup> [www.comhairlenanog.ie](http://www.comhairlenanog.ie)

<sup>13</sup> [www.comhairlenanog.ie](http://www.comhairlenanog.ie)

<sup>14</sup> The National Carers' Strategy: Recognised, Supported, Empowered. Department of Health, 2012.

<sup>15</sup> Department of Children and Youth Affairs (2015) National Youth Strategy 2015–2020. Dublin: Government Publications. Available at: [www.dcyia.ie](http://www.dcyia.ie)

Objective 2.2 of the National Carers' Strategy specifies the need to 'Support children and young people with caring responsibilities and protect them from adverse impacts of caring responsibilities'.

Under the National Carers' Strategy, co-ordinators have been appointed to twelve Children and Young People's Services Committees (CYPSC), with specific young carer initiatives implemented in Donegal and proposed in Galway and Roscommon<sup>16</sup>. Where supports are available, and are presented to the young person, the experience can be very positive, according to a 2009 paper by Finnerty and O'Connell<sup>17</sup> on young carers in West Cork. The young carers they interviewed noted the benefit of a more supportive schooling environment which took their caring responsibilities into account and allowed them to return to formal education in spite of the limits placed by their caring responsibilities. The need for real understanding of the importance of young people's experiences was highlighted in **Youth Work Ireland's Youth Participation Policy (2015)**, which notes that 'actions in youth work need to be informed by evidence; we can take this evidence from experience and ideas of young people'<sup>18</sup>. A newly announced project, **Psychosocial Support for Promoting Mental Health and Wellbeing Among Adolescent Young Carers in Europe**<sup>19</sup>, may work towards some of the goals described in this section.

Actions in youth work need to be informed by evidence; we can take this evidence from experience and ideas of young people'.



<sup>16</sup> The National Carers' Strategy Recognised, Supported, Empowered Fourth Progress Report September 2015 – December 2016

<sup>17</sup> Finnerty, J and O'Connell, C. Voices of Hidden Carers in West Cork. Youth Studies Ireland, Vol 1, No 1, Available at [www.youthworkireland.ie/youth-work-centre/resources](http://www.youthworkireland.ie/youth-work-centre/resources)

<sup>18</sup> Youth Work Ireland Youth Participation Policy, 2015, p 14,

[www.youthworkireland.ie/images/uploads/general/Youth\\_Work\\_Ireland\\_Participation\\_Policy\\_Fina.pdf](http://www.youthworkireland.ie/images/uploads/general/Youth_Work_Ireland_Participation_Policy_Fina.pdf)

<sup>19</sup> <http://me-we.eu/>

# Why Do Professionals Need to Understand Young Carers?



It is important to ask why professionals working with young people need to understand young carers. In this regard it is worth looking at the results that arise when young carers engage with services, and at young carers' experience of lack of support. These issues were examined by Sempik and Becker in 2013. Twenty per cent of their survey respondents were currently attending a young carers or young adult carers service. Of these, almost all (95%) felt that their confidence had improved as a result and that they had more friends (87%)<sup>20</sup>. Three-quarters of the young adult carers (18–25 years) in this survey had communicated their caring role to their college or university, but nearly half (45%) still felt there was no one there who recognised them as a carer and helped them.

The Irish State has acknowledged the need for additional support for young carers through Tusla's 50 Key Messages document, which notes:



*Formal service provision combined with awareness raising and a family support approach, is how support should be provided to young carers and has a major influence on the nature of the impact of caring on the carer.<sup>21</sup>*



## Survey of Young Carers

Care Alliance Ireland undertook a survey of young carers using the online tool SurveyMonkey. The survey was developed inhouse. The questions were as open as possible, offering some suggestions to encourage ideas without being proscriptive in what could be contributed. The survey was promoted extensively through social media (the Care Alliance Ireland Twitter account and the National Carers Week Facebook page), and via email to organisations with a remit around supporting young people, both with and without a specific focus on young carers. Five surveys were completed online or in hardcopy, with a further three individuals completing their survey via telephone conversation with the researcher. In the three conversations, the respondents were more forthcoming with their responses allowing a greater depth of information to be sought. The survey questions are available in Appendix 1 of this report.

<sup>20</sup> Sempik and Becker (2013) Young Adult Carers at School; Sempik and Becker (2014) Young Adult Carers and Employment.

<sup>21</sup> 50 Key Messages: Supporting Parents to Improve Outcomes for Children. Tusla Child and Family Agency (August 2013) [www.tusla.ie/uploads/content/Tusla\\_50\\_Key\\_Messages\\_for\\_Parenting\\_Support.pdf](http://www.tusla.ie/uploads/content/Tusla_50_Key_Messages_for_Parenting_Support.pdf)

The eight people, all female, who responded were aged between 18 and 25 years. They were living in both urban (five) and rural (three) communities. They have a range of caring responsibilities from 'about an hour a day' for one respondent to 35+ hours per week for another. The respondent who estimated an hour per day, however, detailed supports she provides throughout the day that, when discussed a little further, she reflected could take longer than one hour when combined.

## What Did Young Carers Tell Us About Their Perception of Supports Available?

Five respondents cited using Facebook as a support tool for themselves to get information or to share their experiences with others, which reflects findings of a 2015 survey of family carers undertaken by Care Alliance Ireland<sup>22</sup>. Only one gave a reason for not using social media,



*[[I] don't want the person I care for to know and think they're a burden or I resent caring for them.*

The idea of family carers hiding their care 'burden' was not uncommon among the group of respondents, with the issue being mentioned by four of the young women. Caring can become a normalised part of life for young people. One of the survey participants described 'always being a carer' for her family member and that it was simply part of her life. She moved away from home for a number of years to attend university but felt guilty for 'handing over' responsibility to her siblings, so was in almost constant touch with her family through texts and phone calls.

Caring can become a normalised part of life for young people

None of the young adult carers had accessed young carer-specific groups or services and only one had ever been asked what supports and services might be of use to her. She did not detail what her response to that enquiry was. Those who responded in conversation did not know of any young carer-specific services they could have accessed when they were teenagers with caring responsibilities. When given the opportunity to identify what supports would be of value, expert resources, peer-to-peer meet ups and professional guidance about caring emerged as the most valuable.

<sup>22</sup> Care Alliance Ireland: Discussion Paper, Online Support for Family Carers: Options & Experiences (2016)  
Available at: [www.carealliance.ie/discussionpapers](http://www.carealliance.ie/discussionpapers)

The importance of peer-to-peer support was noted by one respondent:

'it's easier to talk to people who understand. A lot of my friends haven't a clue about caring.'

After this, the possibility of escaping from the caring role briefly – opportunities to 'forget you're a carer' and social outlets unconnected to caring – were identified as most valuable.

To try to determine how young carers can be involved in developing and accessing the supports they need, the survey asked about ways in which respondents would like to give their perspective. Reflecting the online world in which we now live, six of the young women replied that they would prefer online interaction, with surveys and questionnaires given highest preference, followed by the opportunity to respond to policy drafts and proposals. Given Smail's identification of young carers as members of a hard-to-reach group, online formats may be the easiest way for young carers to give their opinions, assuming they are aware of the availability of these online resources.

Regarding situations such as this, where young carers are not being engaged in proposals around developments that affect them, the UN (2003) has stated:



***Effective strategies are needed to resolve these concerns.***



***Young people have a body of experience unique to their situation, and they have views and ideas that derive from this experience. They are social actors with skills and capacities to bring about constructive resolutions to their own problems.***

It is difficult to extrapolate more generally from the data gathered in this survey given the very small sample size, but it does provide a useful snapshot of the lived experience of a group of young adult carers, juggling caring responsibilities and life outside the home. The young women who responded reflect a somewhat hidden demographic who could and should be supported through public services and policy, but who have not been given an opportunity to engage with service providers.

# How Can We Raise Awareness and Understanding of Young Carer Issues?



One of the benefits of the EPYC project was the discussion and sharing of experiences across five countries. The partners encountered a number of similar challenges in their work:

- **'Children aren't carers.'** A lack of openness from young people and their families about sometimes difficult circumstances can result in young carers not being formally identified. The information gap may lead policy makers to challenge the hidden nature of these young people's experience.
- **'We know about them but ...'** Where young carers are identified and acknowledged, they may be sidelined for more obvious, seemingly more pressing social needs. The lack of understanding about young carers and their needs is an issue which must be addressed to ensure they are kept front and centre of efforts to support them.
- **Lack of co-operation between services.** In many instances, information on young carers is held in silos and not shared across agencies and support services. This gatekeeping means young carers cannot always access the services they need and may in some cases cause young people in need to slip through the cracks.

The experience of the EPYC partners across Europe has been similar to the Irish experience – that actually meeting and engaging with young carers is a challenge. Carers Trust Scotland operates in a society where family carer and young carer initiatives are well established, and so has less difficulty in reaching young carers. It recommends working with young people in the social activities they already participate in and offering carer supports both socially and in school. This was echoed by our Austrian partner, the Red Cross, which sought to implement a young carer programme in an existing youth group. In this case, however, engagement between the care support and the young person's family was difficult, and ultimately limited the outreach. Our Italian partner, Anziani e non Solo, also encountered difficulties in identifying and connecting with young carers, despite extensive outreach activities, as did Pflege in Not in Germany.

From these experiences, it would seem that actually identifying young people with additional caring responsibilities is the first step, and giving them an opportunity to engage is the second. However, given the apparent lack

of awareness of young carers by society as a whole, and the low levels of understanding of their specific support needs<sup>23</sup>, this is a hugely important area that must first be addressed.

Identifying young people with additional caring responsibilities is the first step, and giving them an opportunity to engage is the second.

Youth workers and professionals working with and around young people are motivated and committed to helping them to live their best lives. They are often practical and resourceful. They may be willing to support important campaign work by advocating on issues of importance to the groups they work with, particularly if the project is led by the young people in the service. The relationships they build with young people are based on trust, which is likely to help them guide young carers to reliable supports and resources.

 School and third-level institutions are often seen as safe havens for young carers – a place where they are expected to be for a significant portion of each day during the school or college year.

 Knowledgeable and supportive teaching and ancillary staff can provide an opportunity for young people to place their trust in an independent authority figure who can advise and support them in seeking resources and access to services that will benefit them. Teaching and support staff should consider the possible family dynamics if they think a young person may be a carer and should be alert to possible signs of caring (including unusual tiredness or aches and pains; academic underachievement; mood swings; isolation or being left out).



<sup>23</sup> Baseline surveys of professionals and youth leaders by EPYC partners indicated low and very low levels of awareness and understanding of young carers.

# Conclusions



Based on the 2014 HBSC data, young carers are significant in number but have limited ability to drive their own agenda. They need the support and guidance of the professionals and youth leaders they encounter to enable them (1) to identify as being in need of support, and (2) to give voice to the services that would be of real and tangible benefit to them. A newly announced project, *Psychosocial Support for Promoting Mental Health and Wellbeing Among Adolescent Young Carers in Europe*<sup>24</sup>, may work towards some of these goals, but in the interim, professionals and leaders with youth involvement must be aware of and have a basic understanding of the existence of young carers, and the particular challenges they face in their lives. The DCYA publication<sup>25</sup> on participation of seldom-heard young people suggests using principles for engagement rather than blueprints, to allow the particular circumstances of individuals to guide their engagement with officialdom<sup>26</sup>, which is backed up by the UN's 2003 report<sup>27</sup>:

-  *There are no blueprints for developing participatory practice, nor should there be. The imposition of pre-defined methodologies denies young people the opportunity to develop approaches best suited to their unique situations and concerns. What is vital is a commitment to working on the basis of shared principles, rooted in respect for young people's capacities as agents of change, and a willingness to recognize them as partners.*
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Professionals and leaders with youth involvement must be aware of and have a basic understanding of the existence of young carers, and the particular challenges they face in their lives.

<sup>24</sup> <http://me-we.eu/>

<sup>25</sup> DCYA (2015) National Strategy on Children and Young People's Participation in Decision-making.

<sup>26</sup> Kelleher, Seymour and Halpenny (2014) Promoting the Participation of Seldom Heard Young People.

<sup>27</sup> United Nations, World Youth Report (2003) Chapter 10: Youth Participation in Decision Making.



What is vital is a commitment to working on the basis of shared principles, rooted in respect for young people's capacities as agents of change, and a willingness to recognize them as partners.



The opportunity for less frequently heard voices to have their say can be as important to policy development as the data gleaned from more traditional methods such as surveys or other more formal processes. The trust of young people in their facilitators is crucial to this process, however, and youth and other workers may be uniquely placed to bridge the gap between policy makers and young people in need of support in a meaningful way.



*Participation promotes the well-being and development of young people. It is by questioning, expressing their views and having their opinions taken seriously that young people develop skills, build competencies, acquire confidence and form aspirations. It is a virtuous circle. (UN 2003)*

# References and Additional Resources



EPYC project [www.ep-yc.org](http://www.ep-yc.org)

Young Carers [www.youngcarers.ie](http://www.youngcarers.ie)

Spun Out [www.spunout.ie](http://www.spunout.ie)

Care Alliance Ireland (2016) Discussion Paper: Online Support for Family Carers: Options & Experiences [www.carealliance.ie](http://www.carealliance.ie)

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# Appendix 1



## A copy of the survey of young carers

### Young Carers services and supports – your views

#### Who are Young Carers?

Young carers and young adult carers are people between the ages of 13 and 25 who are providing care for a parent, sibling, friend or other close relation who has an illness or disability which may include mental illness or a problem with substance misuse. Young carers provide support in their family by helping with taking on extra, usually adult responsibilities including dispensing medication, feeding, personal care, dressing, or making sure the bills have been paid. The level of care provided may vary depending on the family dynamic and the need of the person being cared for. They may also help the family in other ways, like looking after other brothers and sisters, shopping for food, doing extra washing, or preparing dinner.

#### What is this survey for?

This survey is being undertaken by Care Alliance Ireland as part of the EPYC project. The aim of this questionnaire is to establish the ways in which young carers engage with services and supports available to them and what changes they would make in how these services and supports are developed. The survey is entirely anonymous. The results will be used as a basis for meeting with a group of young carers to discuss the responses in more detail. A report will be written based on the survey and the discussion at the meeting. Quotes from the survey may be used in the report, but will be either anonymous or will be given a fictitious name (eg, Mary, age 15 from Munster). The final report will be made available on our websites, [www.carealliance.ie](http://www.carealliance.ie) and [www.ep-yc.org](http://www.ep-yc.org). There are further details on EPYC below.

If you would like to have further involvement, please include your contact details at the end of the questionnaire and we will be in touch. To discuss the survey or any of the issues raised, please contact Denise at Care Alliance Ireland – [denise@carealliance.ie](mailto:denise@carealliance.ie) / 085 806 2392.

Please note, this survey is for young adult carers over the age of 18. If you are under 18 and would like to take part in this work, please contact Denise directly. If you are a former young carer, please give your answers relating to the time you were a young carer.



## Who is compiling this survey and data?

In 2016 a consortium of six European organisations was awarded funding under an EU funding scheme, Erasmus+ youth programme. The aim of the project is to increase awareness of and support for young people with additional caring responsibilities. Care Alliance Ireland is the Irish partner. The multinational project was designed to develop and share innovative practices and promote co-operation.

The target audience of EPYC is professionals and volunteers who work with and around young people, some of whom may be carers.

The project runs from August 2016 to July 2018. You can find out more about EPYC at our website, [www.ep-yc.org](http://www.ep-yc.org).

### Questions:

#### 1: What is your age in years?

18  19  20  21  22  23  24  25  over 25

#### 2: Are you

Male  Female  Prefer not to say

#### 3: Where do you live?

#### 4: Do you consider where you live to be rural or urban?

Rural  Urban  Don't know

#### 5: Approximately how many hours of care do you provide per week?

1-4  5-9  10-14  15-19  20-24  25-30  30-34  35+

#### Other (please specify)



**6: Do you use social media (eg Facebook, Twitter, Instagram, dedicated information websites, etc) for support around your caring responsibilities? This could be in the form of getting information about being a carer or sharing your experiences with others.**

**If yes, please give details like the type of social media you use, or what groups or sites you check on a regular basis.**

- |  |   |
|--|---|
| Facebook – general <input type="checkbox"/>          | Young Carers Ireland <input type="checkbox"/> |
| Facebook – specific groups <input type="checkbox"/>  | Chat groups <input type="checkbox"/>          |
| Twitter <input type="checkbox"/>                     | WhatsApp <input type="checkbox"/>             |
|  | Instagram <input type="checkbox"/>            |
| Others, please give details <input type="checkbox"/> |   |

**Please tell us about the other supports you use**

**7: If you don't use social media to get support around your caring responsibilities, could you please tell us why?**

**8: Do you have any 'real-life' social supports outside your family, eg Guides/Scouts, youth clubs, college societies, sports clubs, neighbours, friends, community groups? These groups do not need to be specific to your caring and may or may not know about your role as a young carer.**

**Yes**                       **No**

**Are these useful? Can you tell us why or why not?**



**9: If you do not have access to these supports, would you like to?**

**Yes**  **No**

**Can you explain why?**

**10: Do you know of any supports available to you as a young carer?**

These may be provided through your school or college, your GP or local health clinic and could include such things as counselling; peer support; online support groups; meet ups; advice on medical or other needs of the person you are caring for; advice on any entitlements you or your family may have.

**Yes**  **No**  **Don't know**

**Could you please list any you know about here?**

**11: Are the supports you know about useful to you?**

**Yes**  **No**  **Don't know**

**Can you explain why?**



**12. Have you ever been asked what supports and services you might use as a young carer?**

Yes  No

**If yes, could you tell us about it?**

**13: What supports and services would be useful to you as a young carer? We have suggested some below but please include any others you can think of.**

- Private online chat groups
- Access to respite for you or your family members
- Peer-to-peer meet ups
- Opportunities to ‘forget you’re a carer’ for a little while
- Professional advice lines about caring
- Social outlets unconnected to caring

**Any other supports and services you would like to see**

**14: What would be the easiest way for you to give your opinion about what services and supports would be useful to you? You can pick from the list below or add any others you that you can think of.**

- Surveys/questionnaires online
- Surveys/questionnaires in person
- Discussion groups online
- Responses to ideas for new or changing services or supports
- Discussion groups in person
- Email responses



**Any other methods you can suggest**

**15: Is there anything else you would like to tell us about your experience of supports and services for young and young adult carers?**

**Thank you for taking part in this survey. We really appreciate your time and the information you have shared with us.**

**This survey is anonymous, but if for any reason you would like to get in touch with us, please email [denise@carealliance.ie](mailto:denise@carealliance.ie). If you would like to take part in a meeting with the project organisers to discuss services and supports for young carers, or to join a discussion group about the findings of this survey, please leave your contact details below. All contact details will be held in strict confidence.**

**The report which will come from this survey and the discussion groups will be published on [www.carealliance.ie](http://www.carealliance.ie) and [www.ep-yc.org](http://www.ep-yc.org) in May 2018. If you would like to find out more information about young carers in Ireland, please visit [www.youngcarers.ie](http://www.youngcarers.ie) or [www.familycarers.ie](http://www.familycarers.ie). You can also access support on [www.spunout.ie](http://www.spunout.ie).**

**If you would like to participate further in this work, please include your contact details below.**





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