MARCH **2023**

SHARING The Caring: **Young Carers'** Experiences and Access to Supports in Ireland

Family Carers Ireland
No one should have to care alone

Young Carers
No one should have to care alone

ISSU
IRISH SECOND-LEVEL STUDENTS' UNION

IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

UNIVERSITY OF LIMERICK
OLLSCOIL LUIMNIGH

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EXECUTIVE SUMMARY

Young carers and young adult carers represent a ‘hidden’ population, often invisible to educators, employers, health professionals and society. Young carers are children under the age of 18 who provide regular and ongoing care and emotional support to a family member. Young adult carers are defined as a separate and distinct group aged 18-24 who provide or intend to provide care, assistance, or support to another family member on an unpaid basis. These young people carry out significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult.

The YOUNGCARERS research project (2022-2023), a collaboration between Family Carers Ireland, University College Cork (UCC), the University of Limerick (UL) and the Irish Second-Level Students’ Union (ISSU), funded by the Irish Research Council New Foundations programme, aimed to gather new evidence about the experiences and support needs of young carers and young adult carers in Ireland, which has heretofore been under researched. This report shares key insights from young and young adult carers across a range of themes, including education, employment, health and wellbeing and relationships, embedding the young carer voice throughout.

Drawing on findings from a national survey of young carers (n= 131) and seven participatory workshops, there are clear findings about the impact of caring on young people. Young carers experience a complex spectrum of positive and negative experiences associated with caring, which impact their health and well-being and make it difficult for them to engage in social, leisure, employment/training or education opportunities. Stress and loneliness are common shared experiences. Worryingly, many are at risk of depression. Balancing care demands with school and employment is challenging for many, with teachers and employers unaware or lacking understanding of the caring responsibilities shouldered by their pupils or employees. Support needs identified by young carers and adult carers included improved identification (both self-identification and identification by those around them), awareness campaigns about what it’s like to be a young carer or adult carer, educational supports, supports for physical and mental well-being, financial supports, and social supports.

Young carer voices were informed key recommendations in relation to ongoing and future service provision, research and advocacy conducted by Family Carers Ireland and stakeholders involved with young carers. We hope that this research will lead to better supports for this ‘hidden’ population and to increased recognition of their contribution to their families, schools, workplaces, communities and societies.

KEY FINDINGS

YOUNG CARERS (n=83)

SURVEY NUMBERS

80% ARE AT CLINICAL RISK OF DEPRESSION

86% FEEL STRESSED

94% FEEL THAT THEY ARE LEARNING USEFUL THINGS BY CARING FOR A FAMILY MEMBER

56% FEEL LIKE THEY CAN'T COPE

27% DO NOT FEEL THAT THEY HAVE ADEQUATE TIME TO SPEND ON SCHOOLWORK

32% STRUGGLE TO BALANCE SCHOOL WITH CARING

YOUNG ADULT CARERS (n=48)

SURVEY NUMBERS

64% ARE AT CLINICAL RISK OF DEPRESSION

79% FEEL VERY LONELY

98% FEEL STRESSED

98% FEEL THAT THEY ARE LEARNING USEFUL THINGS BY CARING FOR A FAMILY MEMBER

71% FEEL THEY CAN'T COPE

61% STRUGGLE TO BALANCE CARING WITH WORK

51% DO NOT HAVE ENOUGH TIME TO SPEND ON THEIR STUDIES

KEY RECOMMENDATIONS

1. Establish a cross-departmental working group on young carers and identify the Department with lead responsibility.

2. Improving identification of young carers, both self-identification and identification by those around them, through a targeted national young carers self-identification campaign, training for professionals coming into contact with young carers and development of a young carers policy in all educational settings, including the identification of a young carer champion.

3. Supporting the transition of young carers to further, higher education and apprenticeships via access programmes.

4. Dedicated funding for young carers to access counselling or psychological support from professionals familiar with the challenges of caring.

5. Supporting young carers financially, through educational bursaries, the introduction of a Young Carer Grant, similar to the successful grant launched in Scotland in 2019 and increasing carer payments to ensure they meet the needs of caring households.

6. Accurate enumeration of young carers, through Census awareness campaigns and the introduction of a young carer question in the Census at School.

7. Active support for young adult carers to engage and remain in employment.

8. Access to a minimum of 20 respite days per year provided free of charge, for caring households.

9. Inclusion of young carers in the refreshed National Carers Strategy.

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INTRODUCTION

Many children and young people in Ireland help care for their parents, siblings, other relatives or friends due to chronic illness, mental-health challenges, disability, alcohol or substance misuse. For these young people, caring can have a profound impact on their childhood, adolescence and early adulthood. While being a young carer can have many positive benefits, it can also negatively affect a young person's health, social life, and self-confidence. Caring can also negatively impact education and employment experiences and outcomes and can have lasting effects throughout the life course.

YOUNG CARERS are children 'under the age of 18 who provide *regular* [italics in original] and ongoing care and emotional support to a family member who is physically or mentally disabled or misuses substances' *(Research in Practice, 2016, p. 2)*. They carry out significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult.

YOUNG ADULT CARERS are defined as a separate and distinct group aged 18-24 who provide or intend to provide care, assistance, or support to another family member on an unpaid basis *(Eurocarers Policy Paper on Young Carers)*. As members of this group are emerging adults, trying to distance themselves from their families and become autonomous, they have needs which need to be considered separately *(Boumans and Dorant 2018)*.

The Health Behaviours in School-Aged Children 2018 survey found that over 13% of 10–17 year olds provide regular unpaid care (Health Behaviours in School-Aged Children 2018 survey). This suggests **that there are approximately 67,000 young carers in Ireland aged between 10-17 years who provide regular unpaid care** (Young Carers in Ireland: Insight into the Prevalence and Experiences of Young Carers in Ireland using data from the HBSC 2018 Study). These young people play an increasingly essential role in the maintenance of family members, filling in caregiving gaps and helping to meet the needs of family and friends.

YOUNG CARERS ARE OFTEN AN *'INVISIBLE POPULATION'* AND SUBSEQUENTLY ABSENT IN SOCIAL POLICY AND PRACTICE.

Young carers often do not identify as carers, instead seeing themselves as a daughter, son, sibling, grandchild, or friend. Self-identifying as a young carer is further complicated by societal norms around caring, whereby adults are typically expected to provide care for other adults and children, whilst young people are not expected to be caregivers but rather care recipients. As a result, young carers are often 'hidden' and subsequently absent in social policy and practice. Their voices and their needs have been largely missing from national dialogues on care, young people, and family wellbeing. This research draws on the voices of the young people themselves to show how caring can be a positive experience, leading to feelings of pride and competence. However, this report also shows how the costs and consequences of caring can be heavy, with some young people taking on high levels of care and experiencing challenges in multiple areas of their lives. The demands of young caring typically come at a time when young people are facing the challenges of adolescence, completing school, entering the labour market or third-level education, and making important decisions about their futures. Many young carers trade time with friends, at school or on their own for the responsibilities of caring. This can put their mental health at risk and create difficulties for their future success and wellbeing.

> **“Many young carers trade time with friends, at school or on their own for the responsibilities of caring.”**

Currently, Family Carers Ireland (FCI) supports over 1,000 young carers through membership and a range of programmes and services. The supports offered to young carers include assessments, awareness programmes, advice and information, advocacy and lobbying, one-to-one support, counselling service, training, peer groups, respite activity breaks and events. Since 2021, thanks to time-limited project specific funding from the Community Foundation, such as the Late Late Toy Show Appeal and Dormant Accounts funding, Family Carers Ireland has been able to offer more support to young carers. However, this is just the tip of the iceberg, and a sustained strategy and funding model to support young carers needs to be put in place. A strategic approach to supporting young carers and their families begins with an increased understanding of the unique place young carers hold within the system of family care. Building awareness and developing supports at the community level, in schools, universities, colleges and in workplaces will help mitigate the potentially adverse consequences of caring on young carers and their families.

The challenges faced in supporting young carers in Ireland is exacerbated by the policy landscape, which is characterised as 'emerging' by young carer scholars (Leu and Becker, 2019). This means that there is emergent public awareness and recognition of young carers, with a small but growing research base. However young carers in Ireland have no specific legal rights. While a range of legislation and some services provided for young carers offer partial or indirect recognition, this is often piecemeal and fragmented. This 'emergent' status of young carers in Ireland and the need for inclusion of young carers' voices provided the motivation for the YOUNGCARERS project and for this report.

The report is structured in three parts. It begins by outlining the methodology and results from the national survey of young and young adult carers. It then introduces visuals that were co-designed by young carers in workshops to represent their caring roles and their support needs. The final section introduces the recommendations, which have been shaped by the young people themselves.

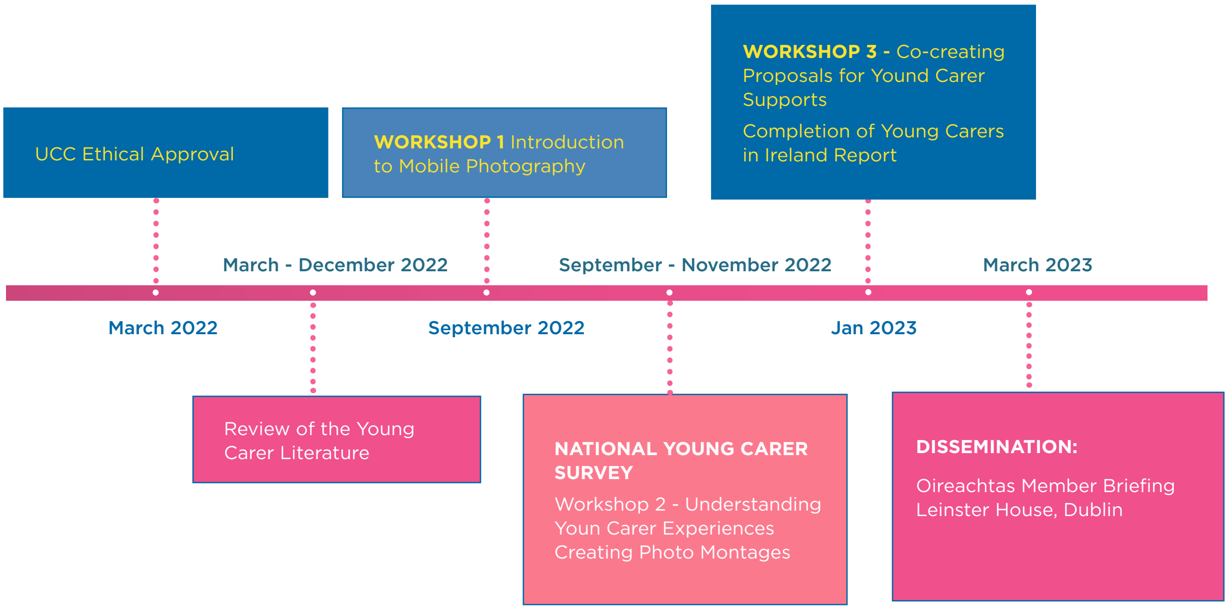
ABOUT THE YOUNG CARERS PROJECT

The YOUNGCARERS research project is a collaboration between **Family Carers Ireland, University College Cork (UCC), the University of Limerick (UL) and the Irish Second-Level Students' (ISSU),** funded by the **Irish Research Council New Foundations** programme. The aim of the research was to gather new evidence on the experiences and support needs of young carers and young adult carers in Ireland. This report identifies the key findings of this research, highlighting implications for policy and practice. It shares insights from young and young adult carers across a range of themes, including education, employment, health and wellbeing and relationships, embedding the young carer voice throughout. These insights will help to inform ongoing and future service provision, research and advocacy conducted by Family Carers Ireland and stakeholders involved with young carers.

This research employed mixed methods to explore the experiences and support needs of young carers and young adult carers in Ireland. Its aim was to investigate the following research questions:

- **What are the experiences of young carers and young adult carers regarding caring, study, work, social networks and accessing services?**
- **What are the support needs of young carers?**
- **How might we co-create support proposals with young carers, for young carers?**

The Key Stages of the YOUNGCARERS Project:



UCC Ethical Approval

WORKSHOP 1 Introduction to Mobile Photography

WORKSHOP 3 - Co-creating Proposals for Yound Carer Supports

Completion of Young Carers in Ireland Report

March - December 2022

September - November 2022

March 2023

March 2022

September 2022

Jan 2023

Review of the Young Carer Literature

NATIONAL YOUNG CARER SURVEY

Workshop 2 - Understanding Youn Carer Experiences Creating Photo Montages

DISSEMINATION:

Oireachtas Member Briefing Leinster House, Dublin

1. Review and synthesis of the young carer literature and policy/non-policy supports[1]
2. National Young Carer Survey - a survey of Young Carers (N = 83) and Young Adult Carers (N = 48) in Ireland July and October, 2022[2]
3. Participatory workshops (n=7), which explored young carers'(n=9) and young adult carers' (n=5) experiences, needs and the core issues impacting their emotional, physical, social, and psychological wellbeing, before co-designing proposals for more targeted carer support to best meet their identified needs[3].
4. Report on young carers' experiences and access to carer support in Ireland (March 2023).
5. Dissemination, including briefing members of the Oireachtas in Leinster House (March 2023).

Increased policy attention is driving a demand for research on issues that affect children and young people. The Irish Government Department of Children, Equality, Disability, Integration and Youth's Statement of Strategy 2021-2023 promotes research with children and young people to design interventions for their needs. Engaging young people in research has been found not only to increase participation (Rouncefield-Swales et al., 2021), but also to indicate that young people can benefit from skills and opportunities to make contributions to society through decision-making (Hacking and Barratt, 2009). In the context of this study, coproduction is central to the development of the YOUNGCARERS project, with young people seen as active partners who provide expert information and insights as to how young carers in Ireland might be better supported. **Co-production refers to the meaningful involvement and active participation of young carers in explicitly described, defined and auditable roles or tasks during different stages of the research project, including the co-development of proposals of young carer supports, policy priorities and dissemination pathways.**

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[1] See Appendix A for synopsis of the literature on Young Carers

[2] See Appendix B for survey methodology

[3] Appendix C for workshop methodology

SECTION 1: FINDINGS FROM THE NATIONAL YOUNG CARER SURVEY

A national survey of young carers (n = 83) and young adult carers (n = 48) in Ireland was conducted in July and October, 2022 (for detailed methodology see appendix B). The key findings and themes which emerged from this survey are outlined below.

83 Young Carers	**48 Young Adult Carers**
AGES RANGED FROM **9-17**yrs (M = 14.08, SD = 1.98)	AGES RANGED FROM **18-24**yrs (M = 20.94, SD = 2.28)
69% FEMALE	**71%** FEMALE
84% OF YOUNG CARERS LIVE WITH THE PERSON THEY PROVIDE CARE FOR	**88%** OF YOUNG ADULT CARERS LIVE WITH THE PERSON THEY PROVIDE CARE FOR
4/5 YOUNG CARERS HAVE BEEN PROVIDING CARE FOR 2+ YEARS	**4/5** YOUNG ADULT CARERS HAVE BEEN PROVIDING CARE FOR 2+ YEARS

PROFILE OF CARING RELATIONSHIPS AND CARE TASKS

Like all young people, young carers are diverse in their experiences and needs. The experience and effects of caring are not the same for each group of young and young adult carers. The nature of the caring relationship and the needs or circumstances of the person needing additional care vary *(See Table 1 and 2).*

1 in 5 YOUNG CARERS AND YOUNG ADULT CARERS PROVIDE CARE FOR TWO OR MORE PEOPLE.

TABLE 1: YOUNG CARERS' AND YOUNG ADULT CARERS' CARE RELATIONSHIPS[4]

PROVIDING CARE TO:	YOUNG CARERS (%)	YOUNG ADULT CARERS (%)
A SIBLING	72	44
A PARENT	28	33
A GRANDPARENT	6	6
OWN CHILD	-	17

4 in 5 YOUNG CARERS CARE FOR SOMEONE WITH MEDICAL AND PHYSICAL DISABILITIES.

1 in 3 YOUNG CARERS AND YOUNG ADULT CARERS CARE FOR A PARENT.

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[4] Many carers reported providing care for more than one person. Thus, percentages exceed 100%. This table displays the most commonly reported caring relationships. Other care relationships reported include caring for one's father (5% YCs, 6% YACs), spouse/romantic partner (2% YACs), and other (6% YCs, 10% YACs).

> *I care for my sister, my grandparents, my great grandmother, my aunt and my mother. At the moment, a typical day for me would be going up and down to my nanny's house throughout most of the day, as she only lives one house down from mine. I help look after my aunt and sister and help her move around. I'd have to say, in all honesty it does impact my education fairly heavily as I'd sometimes have to take a couple of days off to look after and help my sister and everyone.* **(Young Adult Carer, 18 yrs)**

TABLE 2 - CONDITION OF THE PERSON NEEDING ADDITIONAL CARE[5].

CARE NEEDS OF THE FAMILY MEMBER	(%)
MEDICAL AND PHYSICAL DISABILITIES	88
NEURODIVERSITY	24
INTELLECTUAL AND LEARNING DISABILITIES	8
MENTAL HEALTH ISSUES	8
SIGHT AND HEARING IMPAIRMENTS	5
PROBLEMS RELATED TO OLD AGE	2

30% OF YOUNG CARERS AND 42% OF YOUNG ADULT CARERS FELT THAT THE AMOUNT OF TIME THAT THEY SPENT CARING HAS INCREASED SINCE THE START OF THE PANDEMIC.

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[5] The percentages reflect the numbers of young carers and young adult carers who reported caring for someone with a condition in each category. The majority of carers reported caring for an individual who suffered from multiple comorbidities . In total, 178 different conditions, illnesses and disabilities were reported, and were allocated to categories adopted from the Department of Social Protection and Employability Dublin South (Types of disabilities).

The amount and type of care provided varies considerably from carer to carer - from providing a few hours a week for shopping, collecting medication and taking someone to medical appointments to more intense caregiving, such as providing emotional support and companionship, carrying out personal care tasks (e.g. helping with washing and toileting), and assisting in household, domestic management and financial matters. On average, young carers reported providing a high level of care, compared to peers[6]. All young carers provide emotional care and domestic care. Similarly, all young adult carers reported providing very high levels of care[7], when compared to their peers. All provide high levels of emotional and domestic care, and the majority also helped with personal care tasks (88%) and household management (97%). This may mean that, with increasing age, comes increased responsibility (Becker and Sempik, 2018).

Young Carers' Health and Wellbeing

Caring for a loved one can be a positive experience, allowing carers to grow personally, to gain a sense of competency in the caring role (Aldridge and Becker, 1993) and to feel useful and good about themselves (Abraham and Aldridge, 2010). Several studies show that caring at a young age can be associated with increasing maturity, closer relationships with parents and an ability to foster qualities of compassion and empathy (Joseph et al., 2020; Stamatopoulos, 2018). Caring can also help develop resilience and positive coping skills (Boumans and Dorant, 2017). However, research also indicates that caring can have significant negative impacts on children's and young people's health and wellbeing, putting them at increased risk of poor health outcomes, such as depression (Gallagher et al., 2022).

> *The positive impacts of caring are everything about the person we care for. I absolutely love my sister, she means the world to me, since day one. I love caring even during the tougher times. I have never, and I mean never, not wanted to care for her. She completely changed my perspective on life. Before, I never thought about so many issues. Real life. I was dreaming about my life and how all goes well and easy. But my sister teaches me a lesson every day: how to be happy with small things. I think that even though it is hard, she connects our family like glue. I find strength in my heart to fight for her. And fight with her. She helps me to be a better person. To make this world better.* **(Young Carer, 13 yrs)**

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[6] M = 15.67, SD=4.66.
[7] M=22.94, SD=6.43.

> *How I see it is that there are way more positive than negative things about being a carer and being a carer really shaped me to be the person that I am today and the skills I picked up along the way and being able to be there for someone when they are in need.* **(Young Adult Carer, 18 yrs)**

In the survey, we measured the impact of caring by asking young carers about the positive and negative impacts that they experienced as a result of their caring role[8]. Table 3 shows that many young carers experience both positive and negative impacts simultaneously. For example, 89% of young carers reported that they like who they are because of their caring role, with 94% reporting that they 'feel good' about helping[9]. However, alongside these positive impacts, there were high levels of stress and loneliness amongst the young carers who responded to the survey, with 86% feeling stressed and 56% feeling like they can't cope due to their caring role. This suggests that whilst there may be some positive benefits to caring, there is also a significant risk of harm[10].

TABLE 3: Young Carers and Young Adult Carers reporting low positive outcomes (< 12) and high negative outcomes (>8) of caring on the PANOC-YC20

	POSITIVE OUTCOMES[11]		NEGATIVE OUTCOMES[12]	
	N	%	N	%
YOUNG CARER	24	34%	24	34%
YOUNG ADULT CARER	13	32%	25	61%

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8 In the survey, the subjective emotional and impact of caregiving was measured using 'The Positive and Negative Outcomes of Caring' (PANOC-YC20), a 20 item self-report questionnaire to be completed by the young carer. It provides an overall index of the subjective emotional and cognitive impact of caregiving, both positive and negative impacts. Scores below 12 on the positive subscale and/or greater than 8 on the negative subscale may indicate emotional distress. The average score on the positive subscale was 13.87 (SD=4.09) whilst the mean value on the negative subscale was 5.85 (SD=4.24). The percentages reflect the numbers of young carers and young adult carers who reported caring for someone with a condition in each category. The majority of carers reported caring for an individual who suffered from multiple comorbidities . In total, 178 different conditions, illnesses and disabilities were reported, and were allocated to categories adopted from the Department of Social Protection and Employability Dublin South (Types of disabilities).

9 The cumulative percentages reported include carers who reported feeling this way 'some of the time' and 'A lot of the time'.

10 One third of young carers also scored higher than 8 on the "negative impact of caring" subscale.

11 The PANOC-YC20 is a 20 item self-report measure used to assess positive and negative emotional and cognitive impacts of caring. PANOC YC20 Scores < 12 indicate a concerningly low amount of positive psychological outcomes associated with caregiving. Examples of positive outcomes include increased coping skills, feeling useful, or feeling closer to family members

12 PANOC YC20 scores > 8 indicate a concerningly high proportion of negative psychological outcomes associated with caregiving. Examples of negative outcomes include feeling lonely, feeling like life isn't worth living, and feeling as though you cannot cope.

Similar to the young carer group, whilst young adult carers also reported positive outcomes[13], such as feeling closer to their family (88%) and feeling like they are doing something good (93%), almost 2 in 3 (61%) reported negative outcomes associated with their caring role, such as stress, loneliness and difficulty coping[14]. The majority (88%) also feel constantly preoccupied about all they have to do. One in ten (12%) young carers reported being dissatisfied or very dissatisfied with their lives. A notably larger percentage of young adult carers (31%) reported being dissatisfied or very dissatisfied with their lives.

Prior studies reveal that having a parent with a chronic illness is associated with a significantly higher risk for internalising problems (e.g. leading to depression and anxiety) and externalising problems (e.g. aggressive behaviour) (D'Amen et al., 2021; Landi et al., 2022). Worryingly, results indicate that 80% of young carers had elevated levels of depressive symptoms, placing them at clinical risk. In the young adult carer sample, a similarly high proportion reported elevated depressive symptoms, with 64% at risk of clinical depression[15]. These results tally with a recent survey of young carers in Europe (n=673), which found higher levels of depressive symptoms reported by young carers than by young people without caring responsibilities (Gallagher et al., 2021).

In the survey, we measured the extent of care provided by young carers[16]. On average, young and young adult carers reported high or very high caring activities. The findings suggest that those young carers who reported high or very high caring activity[17] were more likely to report negative psychological outcomes, like sadness or low self-worth, associated with their caring roles. This suggests that high-intensity caregiving puts young people at increased risk of cognitive and emotional harm. These findings highlight the potentially damaging effect that increased caring activity has on young carers' psychological wellbeing. Similarly, an increased number of caring tasks undertaken by young adult carers led to more negative psychological outcomes[18]. In addition, increases in financial and practical management tasks, emotional care and personal care requirements were associated with an increase in negative psychological outcomes[19]. These findings suggest that certain types of caregiving tasks are potentially more damaging than others to the wellbeing of young people. Thus, efforts may be needed to reduce the number of these tasks being carried out or to mitigate their potentially damaging effects. For both the young and young adult carer samples, an increase in positive psychological outcomes was accompanied by a decrease in negative psychological outcomes, possibly indicative of a protective effect of positive psychological outcomes on wellbeing[20] .

80% OF YOUNG CARERS ARE AT CLINICAL RISK OF DEPRESSION.

64% OF YOUNG ADULT CARERS ARE AT CLINICAL RISK OF DEPRESSION.

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[13] The mean value on the positive subscale was 13.85 (SD = 4.05).

[14] M = 9.83, SD = 5.27.

[15] CESD-20 scores

[16] The MACA-YC18 is an 18-item self-report tool used to assess the extent of caregiving in young people. It provides a total score which indicates how much caregiving responsibilities a young person has, while also assessing caregiving tasks across 6 subscales. For more information on the MACA-YC18, please see Appendix B.

[17] Total MACA scores >= 14

[18] Total MACA-YC18 scores were significantly positively associated with negative PANOC-YC20 outcomes, i.e. r = .365, p = .031, 95% CI .03, .63.

[19] Financial tasks: r = .459, p = .004, 95% CI .15, .69. Emotional care: r = .449, p = .004, 95% CI .15, .68. Personal care: r = .333, p = .038, 95% CI .01, .59.

[20] Positive PANOC_YC20 scores were significantly negatively associated with negative PANOC-YC20 scores, i.e. r = -.624, p < .001, 95% CI .45, .75.

Furthermore, the pandemic has exacerbated many of the challenges faced by young people in caring roles, with 30% of young carers and 46% of young adult carers feeling more anxious since the pandemic began. Moreover, 22% of young carers and 40% of young adult carers feel more stressed about their caring role since the onset of the pandemic three years ago. Such ongoing pressures increase their risks.

> *Caring for someone has impacted my health. Because of my own sickness, I don't have the same amount of energy as an average person would. So it can be physically straining. When I was younger, when my sister was only a baby, I would have to stay awake throughout the night to make sure that she didn't stop breathing. Now I'm just stuck in that loop because it's almost like second nature to me.* **(Young Adult Carer, 18 yrs)**

86% OF YOUNG CARERS FEEL STRESSED.

56% OF YOUNG CARERS FEEL LIKE THEY CAN'T COPE.

98% OF YOUNG ADULT CARERS FEEL STRESSED.

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I really do wish that I could relax and do some activities like local sports during the weekend. I have definitely felt more pressure being put on me since my sister was born. I am a little stressed sometimes because I honestly don't know what to expect after every appointment, such as Crumlin or paediatrics appointments or hearing or eye appointments. I often think about it. When the appointments are over, I am so relieved! And if the news is not what I was hoping for, it can be challenging to smile and be free in mind. I do wish that we had family around; it would be way better. I am worried about the health of my mom, especially. I sometimes just wish that I didn't know about our financial difficulties as well. Also, seeing how little support and services my sister gets, I am worried that these will change to even worse. How will she live in the future? If there is no support when she is a baby, will there be support when she is older? I feel like I have a huge responsibility and I feel that I will have to be around when my parents are old or not around anymore.I am sad many days and wish my sister didn't have to go the hospital that much. It breaks my heart that people aren't so heart-warming to people who are sick or have special needs. **(Young Carer, 13 yrs)**

Loneliness, Isolation and Social Support

Caring can be lonely and isolating, can negatively impact friendships and can lead to less time for selfcare (Smyth, Blaxland and Cass, 2011). Young carers may experience frustration due to having less time to dedicate to themselves and to other close relationships (D'Amen et al., 2021). Young carers may also experience stigma, leading to social withdrawal and risk of bullying at school (Bolas et al., 2007; Grey, Robinson and Seddon, 2008). However, some evidence also shows that social participation and support help combat some of the negative impacts of caring (Gallagher et al., 2022).

I can't go out with my friends very much at all because I am needed at home. If I do meet up with friends, it is usually at my house but I would prefer to go shopping with my mom , worry free. Or I would like to resume some activities I enjoyed before. **(Young Carer, 13 yrs)**

Caring doesn't really impact my social life, as I usually just plan everything around the people I care for. **(Young Adult Carer, 18 yrs)**

79% OF YOUNG ADULT CARERS FEEL VERY LONELY.

The findings on loneliness from the national survey are consistent with other national surveys of carers, with high percentages reporting feeling lonely some or all of the time (Carers UK, 2022). Overall, 14% of young carers reported concerningly high feelings of loneliness[21]. Similarly, 19% of young adult carers experienced high levels of loneliness. Previous research has linked high loneliness to anxiety, depression and insomnia (Megalakaki and Kossigan-Kokou-Kpolou, 2022). Loneliness is also a common complaint of individuals suffering from heart disease, hypertension, strokes and lung disease (Petitte et al., 2015). With research showing negative psychological and physical health outcomes associated with loneliness, care should be taken to help protect young and young adult carers from experiencing loneliness because of their caregiving responsibilities.

When asked about the existence of friends or companions, 31% of young adult carers felt that they did not have adequate friendships and 17% of young carers reported low perceived friendships. Qualitative comments left by the young carers in the survey also suggest that many felt isolated and in need of support, especially respite.

19% OF YOUNG ADULT CARERS EXPERIENCED HIGH LEVELS OF LONELINESS.

22% OF YOUNG CARERS AND 40% YOUNG ADULT CARERS LOST CONNECTION WITH FRIENDS DUE TO THE PANDEMIC.

> *'I mostly think that all I can do is talk to my brother and no one else.'* **(Young Carer)**

> *'I miss out on some events that my sibling can't attend.'* **(Young Carer)**

> *'There's a lack of understanding from peers.'* **(Young Carer)**

> *'It's worse during school holidays when my disabled siblings are home full-time. It's not my parents' fault as they need a break too and have no outside help. Would be so nice to have a summer off and just hang out with my friends.'* **(Young Carer)**

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[21] Loneliness was measured using a 5-item self-report measure, which is a subscale of The National Institute for Health's self-report Toolbox for Adult Social Relationship Scale (NIH-ASR). Friendship was measured using an 8-item self-report measure, which is also a subscale included in the NIH-ASR. For more information, see Appendix B.

‘I don’t feel like I have any support at all. I started to do counselling one day a week but I had to stop because, even in the hour that I took to myself once a week, I was still needed and ended most sessions after 20 minutes. I struggle with my weight, but I comfort eat the stress away. Being a carer is so lonely. I wish that I could get to live some of my life. I’m 24 and never had a night out ever.’ **(Young Adult Carer)**

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Most young carers and young adult carers juggle their caring role alongside school, college, university and/or work. Like other children and young people, they have goals and aspirations. Yet most research on young carers in school highlights the stresses and challenges experienced when combining caring with formal education needs (Becker and Sempik, 2018). Without the right support, young carers and young adult carers are at risk of lower exam results and of spending less time in education. This has consequences for their higher and further education and for employment. Indeed, young adult carers in the UK are four times more likely than other students to drop out of higher education (Kettell, 2018). However, there is little known in Ireland about how young adult carers fare when they transition to third level education.

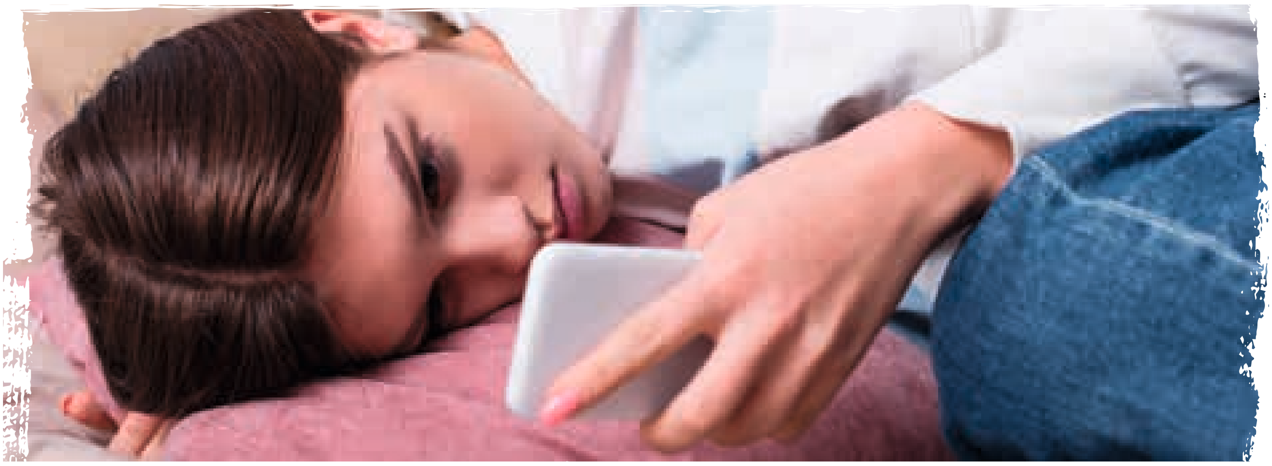
According to the national survey, most young carers were attending secondary school (82%), with much of the remainder being in primary school (15%). In addition to combining education and caring, some young carers reported that they worked part-time (2%) or worked full-time (2%), as well as having full or part-time caring responsibilities[22].

In the young adult carer sample, 73% were attending a Technical/Other University, 4% were in a traineeship/apprenticeship, 23% were working part-time and 15% reported working full-time. Alongside these work and educational commitments, 1 in 3 (31%) young adult carers were caring full-time for at least one person.

1 IN 3 YOUNG CARERS (27%) DO NOT FEEL THEY HAVE ADEQUATE TIME TO SPEND ON SCHOOLWORK

1 IN 3 YOUNG CARERS (32%) STRUGGLE TO BALANCE SCHOOL WITH CARING

1 IN 3 YOUNG CARERS (32%) FEEL THAT THEIR SCHOOLS DO NOT UNDERSTAND THEIR CARING ROLES



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[22] Carers were allowed to select more than one option that applied to them in terms of their education/work responsibilities. Thus, the cumulative percentage does not equal 100

Table 4 shows the extent to which young carers and young adult carers felt that their caring roles impacted their studies and the extent of the support they received in educational settings. Findings show that young carers and young adult carers have different experiences of balancing studying and caring. While many young carers feel that their caregiving demands do not impede on their studies, a notable number of young carers (27%) reported they did not feel that they had adequate time to spend on schoolwork. Overall, 1 in 3 (32%) feel they are struggling to balance school with caring and that their school was not understanding of their caring role. The latter finding is not surprising, since young carers are a largely hidden population, but it also illustrates the importance of formal identification and support within schools. Formal identification and support within schools have been identified as central in promoting academic, social, and emotional wellbeing (Armstrong-Carter et al., 2021) and are key to the academic success of young carers.

In comparison, a large number of young adult carers (over 50%) do not feel they have enough time to focus on their studies. Over 50% of young adult carers struggle to balance caregiving responsibilities with college or university. In both the survey and workshops, many also expressed their concerns about being able to afford studying at third level.

> *Sometimes you can't finish your homework because there may be an appointment or something. Often I have to go to appointments with my mom if it is in the afternoon. If we are in a situation where she can't get or afford a babysitter for my brothers, I leave school early to take care of them in the car while she is in the hospital. My dad is working and sometimes he is not able to be there. Teachers should definitely be told that it's not the fact we are lazy if our schoolwork is not done but sometimes we are very busy doing it and exhausted after long days.* **(Young Carer, 13 yrs)**

51% "OF YOUNG ADULT CARERS DO NOT HAVE ENOUGH TIME TO SPEND ON THEIR STUDIES."

> *'I have no time for study.'*
> **(Young Carer, Workshop)**

> *'I'm worried about getting a new teacher in September] as the next teacher may not be as understanding...I will worry all summer over it.'* **(Young Carer, Workshop)**

> *'[I'm] worried about the financial cost of continuing education in the future.'*
> **(Young Carer, Workshop)**

> *'[I] want to study or do homework but sometimes just don't have the time.'*
> **(Young Carer, Workshop)**

TABLE 4: PERCENTAGE BREAKDOWN OF YOUNG AND YOUNG ADULT CARERS' LEVELS OF AGREEMENT WITH STATEMENTS RELATING TO EDUCATION.

	YOUNG CARERS %			YOUNG ADULT CARERS %		
	Disagree/ strongly disagree	Neither agree/ disagree	Agree/ Strongly agree	Disagree/ strongly disagree	Neither agree/ disagree	Agree/ strongly agree
I have enough time to spend on my school, college or university work	27	9	64	51	24	24
I struggle to balance caring with school, college or university	51	12	37	31	18	51
My school, college or university are understanding about my caring role	32	43	25	33	31	36
I get help from my school, college or university to balance caring and school work	57	32	12	72	18	10
I have someone in school, college or university who I can talk to	41	13	46	58	24	18

On average, young and young adult carers reported high and very high levels of caregiving activity, respectively. This may help explain why so many are struggling to balance education and caring. Worryingly, more than 4 in 10 (41%) young carers and 6 in 10 (58%) young adult carers do not feel they have someone to speak with in school, college or university about their caring role. With research showing extremely high dropout rates amongst young adult carers in third-level education (Kettell, 2018), supporting these carers to find a healthy balance between caring and education is essential.

The overall picture from the survey is consistent with international literature – that young carers and young adult carers alike may be at a significant disadvantage in terms of educational attainment, as they cannot dedicate as much time to their education as non-carer peers can and they feel unsupported, with their needs not well understood. The finding about not having enough time is of particular importance to young adult carers in third-level education, where workload demands are higher, and young people have more time commitments, such as lectures, tutorials and assignment preparation.

Young Carers and Employment

Taking on caring responsibilities while also working in paid employment can present significant challenges for anyone with a caring role. This is especially true for young carers, who are at the start of their working lives. Absence, lateness or having to leave early can damage job security and chances of promotion, while also causing stress (Sempik and Becker, 2014).

51%

ALMOST TWO IN THREE (61%) YOUNG ADULT CARERS WERE STRUGGLING TO BALANCE CARING WITH WORK.

52%

OVER HALF OF YOUNG ADULT CARERS (52%) DID NOT FEEL SUPPORTED BY THEIR EMPLOYERS IN RELATION TO THEIR CARING ROLE.

> *‘Employers do not always understand when you cannot be available for work or that someone you care for has specific needs. Working from home can be difficult due to noise and having to be present’* **(Young Adult Carer, Workshop).**

'I wish I could do more trips with my family, and we don't need to worry about money. Since my sister was born this is often a discussion topic when planning days out.' **(Young Carer, Survey)**

'I would like to have a special day for me alone with my parents, maybe one day a fortnight with my mam and then one day a fortnight with my dad. My brother doesn't sleep even though he is on medication, this means my mam and dad are very tired and we don't have anyone to help them get any sleep.' **(Young Carer, Survey)**

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TABLE 5:
SUPPORTS REQUIRED BY YOUNG AND YOUNG ADULT CARERS IN IRELAND

SUPPORT NEEDS IDENTIFIED/REPORTED	YOUNG CARERS	YOUNG ADULT CARERS
Help with money/finances	13%	35%
Help planning for emergencies	23%	17%
Virtual one-to-one support	8%	8%
Mental health support	23%	33%
Support staying connected to family and friends	13%	17%
Support from a carer service	14%	16%
Help finding ideas for things to do while at home	29%	18%
Assistance from a paid care worker or personal assistant to help them provide care	11%	13%
Educational support	22%	29%
Support which allowed them to have a break from caring	22%	31%
Support to stay healthy	19%	27%
Virtual support network, such as an online support group	7%	4%

Introduction

In addition to the national survey, young carers and young adult carers were invited by Family Carers Ireland and the South Roscommon Young Carers Group to attend up to three workshops to explore their experiences of being a young carer/young adult carer and to co-design support proposals (See Appendix C for detailed methodology).

Collective experiences of young carers and young adult carers

Following an introductory workshop on mobile photography facilitated by a former young carer and professional artist, young carers and young adult carers were invited to photograph images that would represent their caring roles[23]. For example, one young carer shared the following image of walking sticks, with the description: Mum needs these to walk on her own, especially if I'm not there.

FIGURE 1 - Sample photo of the young carer experience, taken by a young carer following the mobile photography workshop.

In the workshops, the groups discussed the images and selected from them to co-create a collective photo montage representing each group's experience of being young carers and young adult carers. They were also asked to select words that would summarise their experiences and to include those words in the photo montages.

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[23] Please note that workshop participants were also guided regarding how to blur the faces of those they pictured to maintain their subjects' privacy and prevent identification.

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FIGURES 2 - 5 REPRESENT THE COMPLEX POSITIVE AND NEGATIVE SIDES TO BEING A YOUNG CARER OR YOUNG ADULT CARER.

FIGURE 2 -

YOUNG CARER WORKSHOP,

8 TO 16 YEARS, *Nov 2022*

Figure 2 depicts the collage created by young carers (aged 8-16 years) in participatory workshops. The top photo is a photo of a young carer's birthday celebrated in a children's hospital, with his family and his ill sister. The top right is a photo of his ill sister when she was a few months old. 'It makes me feel appreciative that she is here now, having spent so long in hospital.' The top middle photo is an important photo for the family.

> *'In this photo, she does not have a tube in her nose, which makes it a bit better. It was the fourth time I saw her, which is nice. She was awake and responding at the time. It was not very often that she would do that.'*

The bottom middle photo represents the time a young carer's sibling was unwell:

> *'This is the shape of a heart. The ENT is wrapped around because all these things were necessary for her feeding. They kept her alive. I put it in the shape of a heart to symbolise that she was like a heart warrior. We had to use all these things to keep her going. It was quite hard at the time as (names sibling) had to be in hospital a lot. It was tough enough as you had school and everything like that.'*

The bottom left-hand photo shows a young carer and her sibling during a family holiday. She explained:

> *'This is a picture that my brother took when I was on holiday. I really wanted a picture of me with (names sibling). I like how she is just listening to me. I think that I was reading her a book at the time. It was very nice, as we were on holiday. It was kind of a relaxing time. As a carer, you have loads of responsibilities. Mam and Dad would be going to the hospital a lot with (names siblings). It was a nice break; we went to (names location). I like it because she is my best friend. She's the only one that does not really judge you. It is very different and it is very nice.'*

The young carer shared how the bottom right-hand photo represents her sister's extended hands:

> *'This picture was kind of hard to take; I really wanted to have her (sister) on my lap. I wanted to take this picture because it reminds me that, through music, you can express your feelings. I wanted to show her hands, as I wanted to symbolise, through music, that we provide extended hands, if you know what I mean. By helping her and always being there for her. But also in real life, day-to-day, if she needs a hand with anything, we obviously have to be there. So that was the purpose of this photo'.*

In terms of words to summarise the collective young carer experience, the group selected the following: warriors (both carers and the family member being cared for), comfort, love and caring, joy, appreciation and family. The group also wanted bright happy colours for the post-its.

On completion of the photomontage, the group then discussed their collective experiences of being young carers. In terms for challenges, they shared that:

> *'It can be hard sometimes.'*

> *'It limits what you can do. You can't go to public places due to Covid and because of the illnesses that you can get.'*

> *'Some people don't understand how you do all these things, not in the sense that it's hard, but in the sense that they don't understand why.'*

> *'People don't really understand what it's like to have a brother or sister in need of care. They might think that there is only a little bit of difficulty and not understand that it is very hard for you.'*

In terms of the positives of being a young carer, the group shared:

> *'There are loads of positives. If you have a sibling with a disability, you understand so much that others don't understand. It's kind of good, as they kind of have a special love for you that no one else would have. Obviously, a parent would love you and there's a special love there, as well. However, if you have a connection with a disabled sibling, there's like no other word to describe it properly. It's kinda hard to describe. It's kinda heart-warming. It's very good to see. They always have this love for you that's so pure and beautiful.'*

> *'I know how to talk about someone who is disabled and put it in a positive way. Most people look at it in a negative way. I can talk about it in a positive way, then they might think in a positive way. I think that is good.'*

Young carers shared that they tend not to share their experiences with friends and peers:

> *'My superpower is having that last thread of hope, having hope.'*

> *'I keep my family business to myself. Most of my friends do know. It's not that they can do much. I kind of keep it to myself.'*

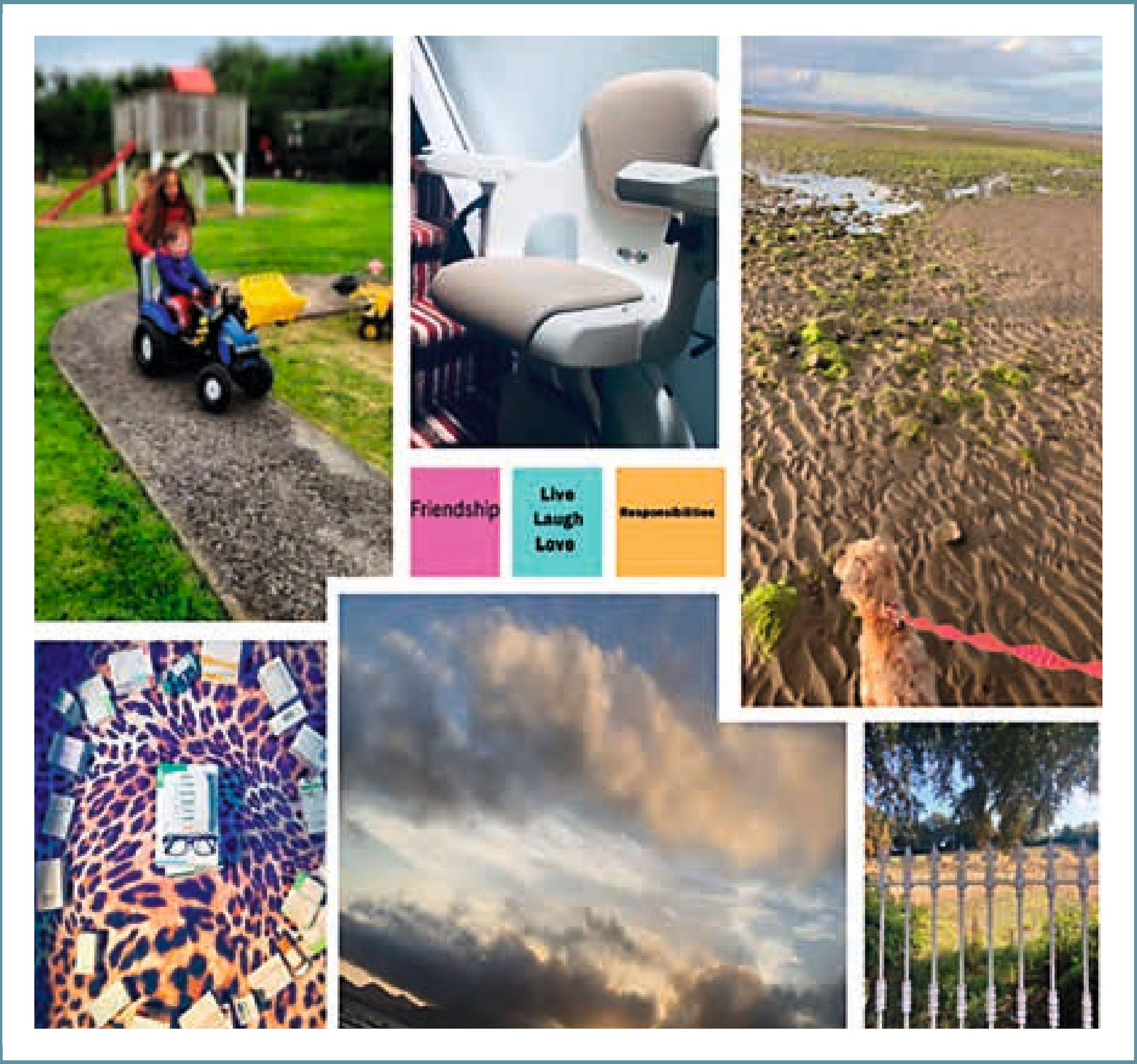

FIGURE 3 - YOUNG CARER WORKSHOP 10-17 YEARS, SEP 2022

Figure 3 illustrates the collective experiences of another group of young carers. The bottom left picture, with glasses and medication arranged in a circle, represents daily life for one young carer. The glasses represent his mother. She has to take medications every day and has to take them in a specific order, at specific times. The bottom middle picture of a beach sky represents the time spent by a young carer with her little brother – a time when she felt really happy. They got caught in the rain and she gave him a jockey back. They laughed. The top left picture represents another happy time, when a young carer pushed her brother in a tractor. By accident, she pushed him onto the grass and he fell. They both started laughing. The top right-hand picture represents a relaxing day out and walking along the beach – family time together for a young carer, her mother, her sibling, and their dog. The top middle picture shows the chairlift belonging to a young carer's mother. He chose this image because his mother has to use it every day to get upstairs to her second room. The bottom right picture of the gate and field represent a calming and mindful walk, finding some peace.

In the workshop, we then discussed the words that describe the shared experiences of being a young carer. These words included: responsibilities, laughing, helping out, having ups and downs. In relation to the good parts, these included ‘helping the people that you love’. In terms of the downs, these included stress.

We further talked about how aware others were of what it’s like to be a young carer. In relation to school, one young carer shared:

> *It’s like when the teachers always give you so much homework, but you still have to help caring, and you still have to do all your homework .*

Another young carer shared:

> *Teachers know that you are a young carer, but they don’t really care, in the nicest possible way. They think that you are like everybody else. They think that you are going out with your friends, as you are not doing your homework.*

Two other young carer siblings individually created separate photo montages of their experiences of being a young carer of a brother with a disability (Figures 4 and 5). The photo montages reflect the accessibility issues faced by their young brother who uses a wheelchair, as well as fun family activities, such as walks by the water, bowling and basketball.

FIGURE 4 - YOUNG CARER INDIVIDUAL PHOTO MONTAGE

FIGURE 5 - YOUNG CARER INDIVIDUAL PHOTO MONTAGE

FIGURE 6 - YOUNG CARER WORKSHOP, 10-17 YEARS, NOV 2022

As illustrated in Figure 6, one young carer explained how his/her sibling who is autistic loved watching Horrid Henry and also has sensory lights with bubbling water to help him/her remain calm, whenever s/he is feeling a bit stressed. Watching him/her being happy made this young carer happy. The word understanding was important, as a young carer felt that society does not fully appreciate her sibling's needs and are not understanding enough. As s/he stated, 'I feel like understanding children with special needs or children is important. S/he can get very violent whenever s/he gets angry and I feel like other people need to understand this. Other people need to understand how they can't really control it. And that's just the way they are.' The word caring represents that: 'As a young carer, you're caring towards your sibling and looking out for him/her'. The words 'non-stop caring' reflected: 'Well, I feel like it's non-stop caring for him at the same time, because like, he's always like on the go or he's like, he's always asking for toys. Or so I feel like I'm glad I'm doing what I can to help him and that like, he has a way of coping with his sadness or any frustration'.

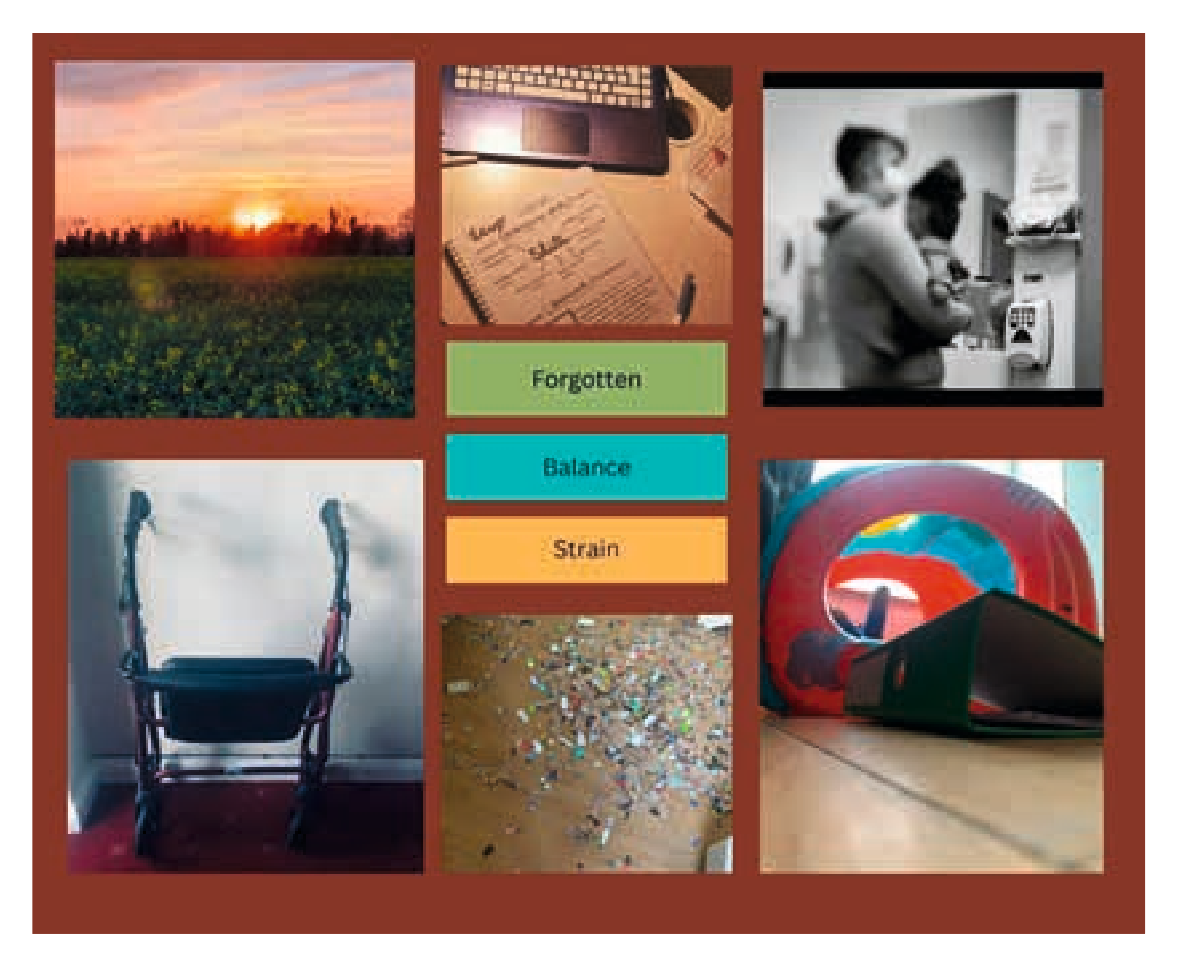

FIGURE 7 - YOUNG ADULT CARER WORKSHOP, 18 TO 24 YEARS, JAN 2023

In Figure 7, the young adult carers shared the meanings of each picture that they selected for the collage. In relation to the bottom middle picture, the young carers stated: '[My sister] shreds everything she gets her hands on, every day. It could happen 3 times a day and I'm the only one she allows to clean it'. The top middle picture and bottom right pictures represents college life: 'I photographed my college folder in front of my son's toys to show I must find time for study and play, trying to have balance in my life'. The young adult carers added:

> *'We do the same as every other student around the country: we go to school, do our work, then come home and study. Sometimes a few bits of homework might be missing, and that's completely okay! It's okay to set priorities and pick something more important, such as family. Schools need to be more understanding and know that every student is doing the best they can and that's all that matters'.*

The top left picture of a sunset and the young adult carers' perspectives: 'Sunsets, no matter how often we deny it, are a powerful tool. Some people think it just happens, like that of a random burst of colours. However, some of us see it as a beautiful, fleeting but powerful moment. It's the same way we see life as young carers. We face so many challenges that it changes our perspectives on life and teaches us not to take anything for granted, so every day is as beautiful as a sunset'.

Challenges faced by young carers and young adult carers and support proposals

In the workshops, young carers and young adult carers also outlined the various challenges that they faced. These challenges include health, wellbeing, social isolation, as well as financial, education and employment challenges. In the final workshops conducted in 2023, the support needs identified by young carers and young adult carers in the survey were further discussed, with a view to having the young carers shape and co-design the recommendation proposals, which we detail below.

Health and wellbeing

Young/young adult carers described an impact on physical and mental wellbeing from caring. The main physical impact being the effect on sleep and energy levels due to their caring responsibilities. However, the majority of the discussion around health and wellbeing was focused on the mental and emotional impacts of caring. These were evidently the areas of their health most greatly impacted. The young/young adult carers reported to feeling stressed, overwhelmed and worried, which mirrors the results from the survey. Young/young adult carers reported negative impacts on their health and wellbeing due to feelings of guilt and isolation. The feelings of guilt were shared by several participants due to pressure to be at home to provide care. This pressure and feelings of guilt could result in young carers not availing of support or not taking breaks from their caring role.

> *‘There’s a lot of pressure to make sure that everyone is okay at home.’*

> *‘[I feel] guilty that I’m not there to help all the time.’*

In addition, young carers and young adult carers reported experiencing the financial strain of social activities and not having free time to spend with friends, which put them at risk of isolation.

> *‘You don’t get much of a social life.’*

> *‘There is peer pressure to maintain a normal social life.’*

> *‘[There’s a] complete lack of awareness and supports; people often are not aware of the challenges faced at home.’*

TABLE 6 HEALTH AND WELLBEING SUPPORT PROPOSALS

YOUNG CARERS	YOUNG ADULT CARERS
Young carer awareness days (e.g. non-uniform days at school)	Access to mental health services Accessible counselling/ psychotherapy sessions Support from outside the immediate family (including extended family) Increasing GP care (e.g. introduce a scheme similar to the NHS pharmacy system and reduce the need for doctors' visits) Opportunities for self-care

Education/Employment

Education comes with many challenges for young and young adult carers. Both young and young adult carers expressed a shared experience of not feeling understood in school or college by their peers or teachers. This made studying very difficult, due to the demands of their caring roles and lack of support from people around them. Many young carers experienced difficulties in studying and completing homework as they did not have time due to their caring responsibilities.

> *'There is pressure from schools to get work done, without considering home circumstances.'*

Both young carers and young adult carers experienced financial barriers to education due to their caring roles. Young carers mentioned not being able to attend extracurricular activities or school trips due to financial strain. They also highlighted that financial strain due to caring caused uncertainty about their future education. One young adult carer mentioned that being a carer is not recognised when applying for education grants. Moving away from home can be a challenge, as the young adult carers would no longer be available to help with the caring role and it could be financially difficult. The young adult carers also highlighted that parents may not be able to support a young carer's education financially due to the costs incurred from providing full time care.

> *'[I'm] thinking of starting to work at a young age to be able to afford education in the future.'*

> *'[There's a] lack of grants and no support financially, making attending college so difficult.'*

> *'Not being able to sometimes afford extracurricular activities [is difficult].'*

Young adult carers also experienced a lack of understanding from employers. As young adult carers have limited time available, work and study must be flexible to allow for both roles. For some, studying or working from home is a challenge due to noise levels, and yet they may need to be present for the cared-for person. As young/young adult carers' caring roles are different, education and employment must be flexible to suit their individual needs.

> *'Work sometimes doesn't understand that I can't be there due to my caring role.'*

> *"Work telling you that you must be available and not understanding why it's not possible.'*

TABLE 7 - EDUCATION AND EMPLOYMENT SUPPORTS PROPOSALS

YOUNG CARERS	YOUNG ADULT CARERS
Increased teacher awareness and understanding of young carers Teachers should be notified about and be aware of young carers and the extra responsibilities that they have. Empathy - teachers should appreciate that it is not always possible to get all homework done, as a lot of time is spent on caring. Teachers also should be involved in raising awareness about young carers, but also be confidential, so as not to single or call people out in class. More academic support, reduced home work when needed. More emotional support. More affordable school lunches, as there is not always time to make lunch at home due to caring. A peer group of young carers at school.	Schools and teachers being aware and understanding the situation, rather than making students feel guilty. Young adult carers being acknowledged/ greater awareness - especially from secondary and third-level institutions. Examples include: talks in schools/ HEIS – similar to anti-bullying awareness campaigns – would help reduce the stigma around caring. Send young carer/young adult carers into schools to talk to students. More leeway for students with caring roles. College supports, grants are needed to ensure young carers can continue education. Caring responsibilities should be considered in grants (e.g. SUSI and HEAR grants). Develop a course for teachers, with increased awareness of young carers and young adult carers. Young carers should be part of this training. Include awareness of the diversity of caring experiences (e.g. may include caring for a sibling, parent etc.). Improve employer understanding of young adult carers. Employers would have a care policy, with some designated days off for caring.

Social Supports

Young carers and young adult carers identified lack of awareness as a barrier to social support. This lack of awareness was mentioned in multiple areas, such as education, society and peer groups. Not feeling recognised or understood creates difficulties for young/young adult carers in reaching out for social support from peers, teachers and professionals.

> *'Schools and teachers being aware and understanding of the situation, rather than guilt given to the students.'*

> *'Awareness, so that more young carers stand up and talk about what they want to help their situation.'*

> *'Friends knowing and understanding that you are a carer. They don't fully understand.'*

Another barrier preventing young and young adult carers from getting social support was a lack of suitable groups and respite. They expressed a need and desire to connect with other young carers who understand their experience and suggested that not having access to this opportunity can lead to feeling isolated or alone.

> *'A young carer social group could build community to help not feel alone.'*

> *'We need better supports for the overall family - respite and home support.'*

We also held two workshops with young carers[24] and young adult carers[25] to explore further what social supports might look like that would help them. The following table outlines their recommendations.

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[24] Young Carer Workshop 23 Jan 2023

[25] Young Adult Carer Workshop 24 Jan 2023

TABLE 8 SOCIAL SUPPORT PROPOSALS

YOUNG CARERS	YOUNG ADULT CARERS
A group/service/support line where someone will listen and talk to you when you are distressed, worried, anxious and someone to help you communicate and process that. Having someone who can relate to how you feel. More recreational and social activities (but above all time). Cheaper extracurricular activities (e.g. school trips). Reduced membership for clubs and sports. Gym passes for young carers so that they can work off stress.	Increased awareness (e.g. public awareness days). Flexibility and customised support – understanding that not every family situation is the same and that some young adult carers may only help a little, while others help a lot. Young adult carer peer groups, build community so as not to feel alone. Young adult carer meet-ups (e.g. days out and opportunities to meet other young adult carers).

Other support needs mentioned by young adult carers included the need for financial support (e.g. some children may care for parents and not get help for it, help with the cost of living and rent). One young adult carer noted that family carers, in general, receive less than the minimum wage for a 24/7 job. Another young adult carer suggested that the Carer’s Allowance be extended to students.

FIGURE 8 - YOUNG CARER REPRESENTATION OF THE FINANCIAL CHALLENGES S/HE EXPERIENCED.

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SECTION 3: RECOMMENDATIONS

As outlined in the introduction, Ireland has been classed as an 'emerging' country in terms of its legislation and policy approach to young carers. By contrast, countries such as the UK have been characterised as advanced in terms of young carer legislation and policy. Advanced status (Leu and Becker, 2017, p. 752) indicates:

- **widespread awareness and recognition of young carers amongst public, policy makers and professionals;**
- **extensive, reliable and growing research base;**
- **specific legal rights nationally;**
- **extensive codes and guidance for welfare professions and national and local strategies;**
- **multiple dedicated services and interventions nationwide.**

This report has provided a snapshot of the experience of young carers and young adult carers in Ireland. The recommendations outlined below are informed by the survey findings participatory workshops, research literature and, most critically, shaped by the young and young adult carers themselves. For Ireland to move from 'emerging' status to 'advanced' status where young carers are supported and empowered, the following recommendations should be implemented.

1. Development of a policy agenda for young carers

As committed to in the National Youth Strategy 2015 - 2020 (action 5.6), the establishment of a cross-sector, multi-departmental and multi-agency working group to jointly address the needs of young carers and support the alignment of young carer supports would help to ensure an integrated and coordinated response to meeting their needs. This would place young carers and young adult carers firmly within the work-plans of TUSLA, the HSE, the Department of Children, Equality, Disability, Integration and Youth (DCEDIY), Department of Education (DoE), Department of Further and Higher Education, Research, Innovation and Science (DFHERIS) and the Department of Health (DoH). Including the voices of the young people themselves in such a working group is critical to enabling them to contribute to and shape the policies that impact them.

While the establishment of a dedicated young carer working group will help address the gamut of young carers needs and avoid them being siloed into one policy area, it is also important to confirm under which Government Department ultimate responsibility for young carers lies. Given the mission of the DCEDIY to 'enhance the lives of children, young people, adults, families and communities, recognising diversity and promoting equality of opportunity', the partners involved in this research recommend that lead responsibility for young carers sits with this Department. The partners also recommend that a specific division within the Department be identified as responsible for young carers and to facilitate regular meetings between key stakeholders and Department officials.

2. Improved awareness of young carers and young adult carers

Improving identification of young carers—both self-identification and identification by those around them—is critical to supporting young carers. This can lead to young people getting early access to support services, reaching out for support when needed and for those supports to be responsive to the specific needs of young carers. The following are important aspects in increasing awareness, visibility and support:

- **A targeted national young carers self-identification and awareness campaign is a vital starting point to support families, communities and wider society identify potential young carers and to be aware of the specific challenges they face.**
- **Young carers and young adult carers are likely to engage with a wide range of professionals, including teachers, youth workers, health and social care workers, and employers. Young carer awareness training is therefore critical for all school staff, youth workers and staff involved in health and social care services, so that they are educated about young carers specific needs, have procedures in place for identifying and responding to young carers and to make the necessary supports available.**
- **Development of a specific young carers policy in all educational settings, including the identification of a young carer champion (an adult in the school who can be an ambassador for young carers) in every school will make ensure that young carers have the support that they need to navigate both their education and their caring responsibilities. At secondary school level, ISSU can support this by mandating that member schools develop policies to recognise and support young carers in their school community.**
- **Inclusion and promotion of young carers under existing funding schemes such as UBU Your Place Your Space, which provides funding to youth services that support young people to develop the personal and social skills required to improve their life chances, is critical to supporting young carers at local level.**

3. Mind the Gap – supporting the transition to further and higher education and apprenticeships

Young carers and young adult carers suggest that the Department of Education and the Department of Further and Higher Education can do more to support young carers. The National Strategy for Higher Education to 2030 (Hunt, 2011) identifies widening access as a key priority facing higher education. Whilst the report does not specifically identify young carers, efforts should be made to include young carers in widening access initiatives across further education institutes in Ireland. This is already emerging in some third level institutions, where young carers are being included in their student support programmes. For example, Family Carers Ireland is currently delivering a programme with the South East Technological University (SETU) supporting young carers transitioning to third level. Such programmes are promising and provide impetus for all further and higher education institutions and apprenticeships to explicitly include young carers in their access programmes, encouraging them to achieve their full potential.

4. Access to targeted mental health supports

Given that many young carers and young adult carers experience poor mental health and wellbeing, with the majority of respondents to the national survey at clinical risk of depression, there is a pressing need to provide adequate and targeted mental health support for young carers. A dedicated counselling service delivered by professionals who are knowledgeable about caring is urgently required by this group of young people. Dedicated funding to establish peer support groups within and outside of school is also required so that young carers feel less alone in their caring roles.

5. Money Matters!

Young carers worry about finances in general but many point to the particular challenges that they face when combining care with paid work and/or studying. Changes to family finances as a result of caring can hamper young carers' abilities to engage in social, leisure, employment or educational opportunities. The following recommendations would address some of these financial challenges faced by young carers:

- **Factoring young adult carers into SUSI and HEAR grants or having a specific young carer bursary would encourage young carers to disclose their carer status and give them the financial support to continue their studies. Some third level institutions in Ireland already have special bursaries for young carers as part of their access programmes. These should be rolled out nationally to financially support young carers transition to third level education.**
- **The introduction of a Young Carer Grant, similar to the one launched in Scotland in 2019, will provide young carers with much-needed financial support and recognition of their caring role. Evaluation of the Scottish Grant showed positive impacts on young carers, enabling them to engage in social, leisure, employment/training or education opportunities that they might not have been able to do otherwise, whilst also providing some recognition of their caring role (Scottish Government, 2021). The introduction of such a grant in Ireland is critical to supporting young carers with some of the costs associated with their caring responsibilities, whilst also helping them to improve their own quality of life.**
- **The adequacy of current carer payments such as Carer's Allowance is not only important to adult carers, but also to young and young adult carers. This is an important issue for young carers since poverty and financial insecurity impacts the whole family unit. Research by the Vincentian Partnership for Social Justice, published in April 2022, shows that before the cost-of-living crisis, income supports for family carers were inadequate for supporting low-income caring households to meet a Minimum Essential Standard of Living (MESL) (MacMahon et al., 2022). A review of eligibility for Carer's Allowance and an increase in the weekly rate of Carer's Allowance to €325 in the interim, as suggested by Family Carers Ireland, should lead to fundamental reforms which would address some of the financial challenges that young people in caring households face[28].**

6. Accurate enumeration of young carers

Young carers often do not identify as carers, but instead see themselves as a daughter, son, sibling, grandchild or friend. Self-identification is further complicated by societal norms around caring, whereby adults are typically expected to provide care to other adults and children, whilst young people are not expected to be care-givers but rather care recipients. As a result, many young carers remain ‘hidden’. This is compounded in surveys and censuses where the head of the household or adult is the respondent[29].

Whilst the aforementioned challenges in enumerating young carers are beyond the control of the CSO, opportunities are available to increase the effectiveness of the Census by raising public awareness of the value of including the care provided by young people in completing the form. Surveys completed by young people themselves are also more likely to provide a more accurate picture of the extent of their caregiving. Therefore, the CSO should work with their partners Scoilnet and the Department of Education, to include a question on young carers in the Census at School. This would enable a much better picture of the number of young carers in schools, as well as having the potential to significantly increase awareness, identification and support[30].

7. Active support to engage in paid employment

Many young adult carers have to perform a difficult balancing act, juggling paid work with their caring responsibilities. They may be compelled to reduce their working hours (involuntary part-timers) or eventually give up paid employment, thereby reducing their incomes and pension entitlements. To support young carers to enter and remain in the workforce, workplaces must create easily accessible and well publicised procedures so that young adult carers can inform their managers or Human Resource departments, in confidence, about their caring roles. Employers need to understand the challenges faced by young adult carers and adopt policies which clearly set out the support and flexibility to the young adult carers in their employment. Where possible, employers should engage with Family Carers Ireland’s Caring Employers Programme, which assists employers to build a supportive and inclusive workplace for staff who are, or will become, carers, including young people. This not only benefits carers, but also delivers real benefits to employers.

8. Give young carers a break

Access to respite services in particular was highlighted as an important topic, with many young carers highlighting the lack of support available to enable them to take a break. Respite is understood as offering an opportunity for young carers to spend quality time with their families, uninterrupted by caring. It is vital that young carers and their families be given the breaks necessary to nurture the wider family unit and to have time for socialising and leisure. The enshrinement of a right to a minimum of 20 respite days, provided free of charge, for caring households in the upcoming statutory home support scheme legislation is critical to delivering this.

[29] A Census 2016 identified 6,108 carers under 18, a total of 0.5 per cent of the child population. By comparison the Health Behaviour in School-aged Children Survey (HBSC) 2018, which is completed by the child, reported 13.3 per cent of 10-17 year olds surveyed (n= 15,557) said they provide regular, unpaid personal help for a family member with a long-term illness, health problem or disability. This amounts to 67,000 young people aged 10-17 providing regular unpaid care.

[30] We note that, beginning in January 2023, the School Census in the UK will include a question on young carers for the first time.

9. Young carers included in the refreshed National Carers Strategy

Ireland's first National Carer's Strategy, published in 2012, contained four actions dedicated to supporting young carers and protecting them from the adverse impacts of caring. The Programme for Government commits to publishing a refreshed National Carer's Strategy with an updated range of actions to ensure that family carers, including young carers are fully supported in a joined up and cohesive way. Having now entered the second term of this Government, the partners involved in this research urge the Government to prioritise their commitment to publish a refreshed National Carers Strategy, informed by the practical, educational and health needs of Ireland's young carers.

APPENDIX A - A REVIEW OF YOUNG CARER LITERATURE

YOUNG CARERS - A HIDDEN POPULATION

Who are young carers?

While the prevalence of young carers in Western societies ranges between 5 to 21% (Chevrier et al., 2022), young carers often represent a hidden and heterogeneous population[31] (Nap et al., 2020), whose caring role may not be recognised or acknowledged by healthcare and other professionals and wider society (Smyth, Blaxland and Cass, 2011). This is because young carers and others may see caring as a normal part of family life, may minimise their caring role and thereby not self-identify as young carers (Saragosa et al., 2022). One of the most common themes reported by young carers is seeking 'normalcy' by concealing their caregiving role from others. This may be to prevent stigmatisation, especially if they care for a parent with mental illness or physical disability (Bolas et al., 2007; Landi et al., 2022b) or due to fear of 'standing out' compared to their peers (Hanna and Chisnell, 2019; Smyth, Blaxland and Cass, 2011). Indeed, young carers tend not to complain and, when identified, are usually seen as being 'in need' rather than 'at risk',' i.e., children who require support as opposed to children who are at risk or vulnerable (Hanna and Chisnell, 2019). Critically, the fact that many young carers do not self-identify as carers often leads to failure to seek out and avail of support (Smyth, Blaxland and Cass, 2011). Self-identification thereby has the potential to empower young carers.

What caring tasks do young carers perform?

Much of the literature on Young Carers has emerged from the UK, from the 1980s onwards (Hanna and Chisnell, 2019). However, while some variation exists in young carer roles across cultures, young carers in all countries tend to carry out a similar range of caring tasks and share similar experiences (Gallagher et al., 2021). However, the scale, scope and duration of caring performed by young carers varies greatly (Cass et al., 2009), due to individual circumstances and the caring contexts. Unsurprisingly, the extent of caring tasks provided by young carers increased in all countries during the pandemic (c.f. Landi et al., 2022). Broadly speaking, youth caregiving comprises a continuum, ranging from undertaking small amounts of caregiving responsibilities – such as basic household chores – to increasingly higher amounts of caregiving duties at the expense of developmental needs (Landi et al., 2022). Young caring activities tend to fall into six areas: domestic tasks and gardening; emotional support; intimate care (toileting, washing, showering, lifting, dressing, and feeding, including administration of medication); supervision of younger siblings; bill payments; and translation responsibilities for non-English-speaking relatives (Research in Practice, 2016).

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[31] A two-round Delphi study conducted with 66 experts on YCs from 10 European countries reported a lack of visibility and awareness about YCs in general, and young adult carers in particular. Although awareness is slowly increasing in most countries, with the UK ranked highest, experts acknowledged that it remains challenging to identify YCs in many countries (Nap et al., 2020).

IMPACTS OF CARING ON HEALTH AND WELLBEING

International studies document the significant impacts caring can have on the health and wellbeing of young carers. Whether a young carer experiences more positive or negative outcomes associated with their caregiving role is impacted by a variety of societal and individual level factors, such as unequal conditions of care (Alexander, 2021), stigma and social isolation (Gray, Robinson, and Seddon, 2008), caregiving responsibilities, identity, and support domains (Janes, Forrester, Reed, and Melendez-Torres, 2021). Therefore, consideration of both the positive and negative effects of caregiving on young carers is vital to fully understand the young carer experience.

A recent European survey found that young adult carers experience both positive and negative outcomes related to caring, often at the same time. Indeed, the survey highlights that caregiving during adolescence is not a wholly negative or detrimental experience for all young adult carers, but can also be a role from which young people learn and grow personally (Bennett et al., 2022; Day, 2017). The ability to carry out competent caring makes young carers feel worthwhile (Aldridge and Becker, 1993), can foster empathy, compassion and a desire to help others (Stamatopoulos, 2018). Caring can also develop resilience and positive coping skills (Boumans and Dorant, 2018), increased self-esteem (Bolas et al., 2007), feeling useful and good about themselves (Abraham and Aldridge, 2010), and increased maturity.

However, an important point to note is that while youth caring has many benefits, it also may place some young carers at risk, particularly if the level of caring provided is significant. Youth caregiving can be stressful and challenging for many young people (Joseph, Sempik, Leu, and Becker, 2020; Wepf and Leu, 2022). The length of time spent caring, the nature and severity of the family member's illness, incapacity or disability (Cree, 2003), the age of the young carer (Dearden and Becker, 2004) all can have potential negative impacts on young carer wellbeing. Studies also reveal that being a young carer can, over the long term, exacerbate health inequalities throughout the life course (Leu et al., 2022). Young people with a sick family member tend to have more mental health problems and more negative impacts behavioural, psychosocial, and academic maladjustment than their peers without a chronically ill family member. Caring for a sick family member may also be quite stressful, as many young people will not have received specific training or support for their caring role (Alfonzo et al., 2022; Eurocarers, 2017). In a recent survey of young carers in six European countries, a relatively high percentage of young adult carers reported thoughts of self-harm or harm towards others due to their caring role. This finding indicates that some young adult carers are at significant risk of mental distress and likely points to a lack of dedicated, appropriate psychosocial and other supports (Bennett et al., 2022).

Young carer isolation and friendships

Caring can be a lonely and isolating experience for some. Loneliness is considered a biopsychosocial stressor, and has been linked to many chronic conditions, such as heart disease, hypertension, stroke, lung disease, obesity, and psychological stress (Petitte et al., 2015). Caring can also negatively impact friendships and lead to less time for restorative and recreational activities (Smyth, Blaxland and Cass, 2011). Young carers may experience frustration due to the decrease in free time available to dedicate both to themselves and to other relationships, including those with their own peers, which could make it difficult to establish intimate relationships (D'Amen et al., 2021). Young carers may also experience stigma, leading to social withdrawal and risk of bullying at school (Bolas et al., 2007; Grey, Robinson and Seddon, 2008). However, social participation and support help to combat some of the negative impacts of caring (Gallagher et al., 2021).

Young carer life satisfaction

Young carers report lower levels of life satisfaction compared to non-caring youth (Pakenham et al., 2006). Additionally, low life satisfaction has been shown to predict increases in depressive symptoms in young carers across 21 European countries (Gallagher et al., 2021). Measures of young carer and young adult carer life satisfaction and subjective wellbeing are also being increasingly considered by policymakers to inform and appraise policy (Dolan and Metcalfe, 2012).

Young carers and the pandemic and Covid-19 Unsurprisingly, the pandemic significantly impacted the psychological wellbeing of young carers across Europe. On a positive note, some young adult carers experienced having more time for themselves, for favourite activities or for self-reflection, as well as having more time with their families, due to online schooling and not having to travel to school (Hanson et al., 2022). However, when compared with non-carers of equivalent ages, young carers and young adult carers experienced more social isolation or were more negatively impacted by not being able to meet up with friends. This, as well as an increased level of caring responsibility and increased worry for the care recipient, affected their wellbeing. Furthermore, worries about school, fear of transferring COVID to loved ones, loss of relatives or postponed treatment/investigations were also mentioned (Hanson et al., 2022).

YOUNG CARERS - EDUCATION AND EMPLOYMENT

Most of the research on young carers in school highlights the stresses and challenges experienced when combining caring with formal education needs (Becker and Sempik, 2018). Caregiving by children and young people internationally has been associated with harmful educational and health outcomes and poor transitions into adulthood (Leu et al., 2022). Specifically, the type of care delivered and the nature of the family members' illness tend to impact school engagement (Moloney, Kroll and Lafferty, 2020). Unsupported and long-term caregiving directly impacts young adult carers' educational opportunities (Day, 2021) and can increase school absenteeism. To meet their caring demands, young carers are likely to skip school, arrive late or need to leave early, thereby experiencing difficulties in balancing school and caring demands (Smyth, Blaxland and Cass, 2011; Stamatopoulos 2018; Vizard et al., 2019; Wong, 2016). UK studies show that young carers are less likely to continue into further or higher education than other young people (Yeandle and Buckner, 2007). Indeed, young adult carers are four times more likely than other students to drop out of higher education (Kettell, 2018). According to international studies, young adult carers are often unemployed, or work part-time in order to be able to carry on with their caring responsibilities. They may have no appropriate qualifications for employment because of the impact that their caring role has had on their education and training (Leu et al., 2018).

YOUNG CARER SUPPORT NEEDS AND REQUIREMENTS

Social supports

A systematic review of the young caregiver journey revealed that young carers have specific informational and emotional needs, such as the need for peer support, self-care tools, skill building and caregiver training (Van der Werf et al., 2022). Social support is an important indicator of psychological wellbeing, with research showing that social participation can moderate the relationship between life satisfaction and depression in young carers (Gallagher et al., 2021). Amongst young people facing parental illness, those who scored highest on physical and psychological wellbeing, high moods and emotions and high social support had the highest health related quality of life (Pilato, Dorard, Chevrier, Leu and Untas, 2022). Previous studies suggest that young carers would welcome having someone to talk to, including their peers, in times of crisis (Van der Werf et al., 2022). Young carers who feel that they have social support, who feel connected to school and who have good coping strategies also experience less stress and better adjustment to the caring situation (Gough and Guilford, 2020; Hanna and Chisnell, 2019).

Educational supports

Educational providers are well placed to identify and support young carers and their families through the creation of a positive school climate and positive relationships between pupils and staff (Gough and Gulliford, 2020). For example, in the UK, the Carers' Trust and the Children's Society jointly developed a set of principles, 'Young carers in schools toolkit', and similar guides for identifying young carers. (Warhurst, Bayless and Maynard, 2022). Similarly, to try to identify young adult carers earlier in their higher education experience and thereby flag any support needs, in 2020, the Universities and Colleges Admissions Service (UCAS) in the UK introduced a tick box for carers on application forms, to facilitate those students who choose to self-identify as carers (Kettell, 2018).

Schools, colleges and universities could work with local young carers and young adult carers groups to ensure that they have appropriate policies and networks to be able to meet the needs of young carers who are pupils and students (Blake-Holmes and McGowan, 2022). However, one UK study found that teachers may find it difficult to identify young carers who did not volunteer this information. Once identified, schools perceived the main areas of need that they could provide support for were the emotional wellbeing of the pupils and additional academic opportunities (Warhurst, Bayless and Maynard, 2022). Young adult carers would like flexibility (e.g. school, university) and to be able to avail of special leave when necessary (Van der Werf et al., 2022). This could be achieved, for example, through the introduction of a carers' card to ensure flexibility in homework and exams, as well as the provision of more holistic support, i.e., guidance on career choices, nutrition, and life management skills (Nap et al., 2020).

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[32] https://carers.org/resources/all-resources/27-supporting-young-carers-in-schools-a-toolkit-for-young-carers-services

APPENDIX B - SURVEY METHODOLOGY

ETHICAL APPROVAL

Prior to the commencement of the project, research ethics approval was obtained from UCC.

SURVEY DESIGN

The survey was designed and disseminated using Qualtrics. The participant information sheet, consent and assent forms and survey were written in clear, easy-to-understand language and described all relevant aspects of the research protocol in full. Informed consent also necessitated that the information sheet and consent form included the foreseen benefits and possible risks of participation, while drawing attention to participants ability to withdraw participation at any time without consequence. In relation to the survey, standardised measures and scales were incorporated. Please find more information on these below:

MACA-YC18 (Multidimensional Assessment of Caring Activities Checklist)

Both the MACA-YC18 and the PANOC-YC20 (see below) are validated psychometric instruments that are now being used in 15 countries (Becker et al., 2022). The Multidimensional Assessment of Caring Activities (MACA-YC18) is an 18 item self-report measure of caring activities to be completed by children and young people (Joseph, Becker, Becker, and Regel, 2009b). It has been designed to provide an index of caregiving activity in young people, ranging across 6 sub-categories: domestic tasks, household management, personal care, emotional care, sibling care, and financial/practical care. Each subscale score has a possible range of 0 to 6, with higher scores indicating greater activity on that domain of caring (Becker et al., 2022). The MACA-YC18 was developed from originally 42 items (MACA-YC42) using exploratory principal components analysis, and offers three response alternatives for each item (0 = Never, 1= Some of the time, 2= A lot of the time). By summing up the responses, an index of the total amount of caring activity can be calculated (range 0–36).

The lowest a person can score is 0, while the highest, indicating greater caregiving activity, is 36 Scores of 10–13 indicate a moderate amount of care activity, scores of 14–17 indicate a high amount and a score of 18 and above demonstrates a very high amount of caring (Joseph et al., 2012). Of course, most children and young people, whether young carers or not, will score somewhere in between these two extremes. The average score for children and young people is 14.

PANOC-YC20 (Positive and Negative Outcomes of Caring Questionnaire)

The PANOC-YC20 for young carers (Joseph, Becker, and Becker, 2009a; Joseph, Becker, Becker, and Regel, 2009b) measures the subjective cognitive and emotional impact of caring on young people and recognises that caring can have both positive and negative effects on a young person's wellbeing. The questionnaire consists of two 10-item subscales assessing positive and negative effects with three

[33] https://www.qualtrics.com/uk/lp/uk-ppc-experience-management/?utm_source=google&utm_medium=ppc&utm_campaign=UKI%w7CSRC%7CBRD%7CQualtrics&campaignid=11697329479&utm_content=&adgroupid=119399815131&utm_keyword=qualtrics%20survey&utm_term=qualtrics%20survey&matchtype=p&device=c&placement=&network=g&creative=481972672927&gclid=Cj0KCQiA2-2eBhClARIsAGLQ2RnFq0xByGlfQXNtxJFDYexj9A3aS6oV3sYvgHa9N4QSQV5n6nlyGfkaAgh6EALw_wcB

response alternatives (0 = Never, 1= Some of the time, and 2 = A lot of the time). The responses are summed up for each subscale (range 0–20), with high values indicating a high amount of positive or negative effect of caring (Järkestig-Berggren et al., 2018). Higher scores indicate a greater positive and negative score, respectively. Scores less than 12 on the PANOC positive scale and/or greater than 8 on the PANOC negative scale may indicate emotional distress, or be interpreted by clinicians as concerning (Becker et al., 2022).

In addition to the MACA and the PANOC, a number of other scales and measures were used. These include the NIH-ASR, the CESD-20 and life satisfaction measures. Please find more detail on each below:

NIH-ASR (The National Institute for Health's self-report Toolbox for Adult Social Relationship Scales)

The NIH-ASR was used to assess social support. Young adult carers completed the Emotional Support (8-items), Instrumental Support (8-items), Friendship (8-items) and Loneliness (5-items) subscales. Young carers completed a modified version assessing Emotional Support (7-items), Friendship (5 items), and Loneliness (7-items) (Dietz et al., 2022). Participants rated the extent that each item reflected their experience over the past month on a 5-point Likert scale, with 1 indicating they felt that way 'none of the time' and 5 indicating 'a great deal of the time'. T-scores were used to assess the social support subscales, as is recommended by the National Institute for Health (Slotkin et al., 2012).

CESD-20 (Centre for Epidemiological Studies Depression Scale)

Depression was measured using the Centre for Epidemiological Studies Depression Scale, which is a 20-item self-report measure that asks how often during the past week an individual experienced symptoms associated with depression, such as poor sleep, restlessness and feelings of sadness (Radloff, 1977). The modified version used has been shown to be suitable for use with young people aged 6-17 (Faulstich et al., 1986). Cut-off scores were applied to determine those young carers and young adult carers at risk for depression. Previous research has shown a cut-off score of 15 to be indicative of depression in children and adolescents (Faulstich et al., 1986), while a cut-off of 16 is optimal in adult populations (Lewinsohn et al., 1977). Thus, we applied these cut-off scores during our analysis.

Life Satisfaction

A single item self-report measure of life satisfaction was used. Research shows single item measures perform similarly to multiple item measures of life satisfaction (Cheung and Lucas, 2014) Carers were asked to rate on a 4-point scale 'In general, how satisfied are you with your life?'. Scale responses included 1 (very dissatisfied), 2 (dissatisfied), 3 (satisfied), and 4 (very satisfied).

SURVEY SAMPLING AND DISSEMINATION

The survey was advertised nationally - through the Irish Second Level Student's Union (ISSU), Family Carers Ireland, South Roscommon Carers group, through the Student Unions at University College Cork, University of Limerick and other Higher Education Institutions throughout Ireland. The research team also emailed the online survey weblink to formal support organisations for young carers. Calls for participation were posted on Twitter, Facebook and Instagram by the Family Carers Ireland.

DATA AND STATISTICAL ANALYTICS

Data were analysed using IBM SPSS Statistics Version 28.0.1.1 (14). Descriptive statistics, including normality tests and frequency analyses, were carried out where appropriate, and means, standard deviations and percentages, are reported. Additionally, inferential tests, including Pearson's and Spearman's rho correlation coefficients and 95% confidence intervals are reported where relationships between variables are examined.

EXCLUSION AND INCLUSION CRITERIA

For psychometric instruments (PANOC-YC20, MACA-YC18, NIH-ASR, CESD-20), participants' data were excluded if they had missing values which accounted for more than 5% of the total scale. Missing data were defined in SPSS as periods. Additionally, participants' data were excluded if they completed the wrong scale for their age category (e.g. participants over 18 completing the paediatric CESD-20). This resulted in the exclusion of 11 participants' data from the CESD-20 and NIH-ASR. However, their demographic information, such as their age, gender, educational attainment and employment status, were retained, as was information collected concerning their experience of education, employment, COVID-19 and qualitative information they shared about their caregiving roles.

APPENDIX C - PARTICIPATORY WORKSHOPS WITH YOUNG CARERS - METHODOLOGY

The workshops were developed around the following three themes:

- Introduction to mobile photography;
- Young carers experiences of caring (individual and collective - using photo-montage);
- Co-creating supports for young carers, with young carers.

The seven half-day workshops took place in July 2022, September 2022, November 2022, and January 2023. The young carer workshops involved young carers between 10-17 years. The young adult carers involved young people between 18 and 24 years of age. To maximise participation, FCI used its existing strong relationships with 1,000 young carers, as well as its strong relationships with national and regional youth organisations. ISS21, the Irish Second level Students' Union (ISSU) and the HEI student unions (access officers) in Cork, Dublin and Athlone also promoted the workshops. ISSU further publicised the workshops through social media and its monthly newsletter which is circulated to students in over 500 secondary schools nationally. Workshops took place online via Microsoft Teams and using the online collaboration tool, Miro.

The first workshop explored the use of photography as a means of capturing experiences, including some tips and tricks in relation to taking photos and photo-editing using the application Snap Seed. The second workshops commenced with sense-making and empathy mapping to explore young carer experiences in the home, school/university and wider society. The third workshop used ideation and visioning tools to co-create proposals for young carer supports in relation to health and wellbeing, education and employment and social supports. All workshops incorporated art-based methods (e.g. photomontage) to optimise participation.

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