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Young carer research project: Summary of findings

July 2020

ABOUT CARERS NSW

Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Our vision is an Australia that values and supports all carers, and our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation.

www.carersnsw.org.au

<https://twitter.com/CarersNSW>

<https://www.facebook.com/carersnewsouthwales/>

ABOUT CARERS

A carer is any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail.

Across NSW, there are approximately 854,300 carers¹ and to replace the care they provide the NSW Government would have to spend more than \$17 billion each year.² Carers come from all walks of life, cultural backgrounds and age groups. For many, caring is a 24 hour-a-day job with emotional, physical and financial impacts that can also affect their participation in employment, education and community activities.

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Carers NSW Policy and Research Team
July 2020

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Carers NSW wishes to thank the young carer research participants, Project Advisory Group members, and other key stakeholders who contributed their time and expertise to this project.

¹ Australian Bureau of Statistics 2018 Survey of Disability, Ageing and Carers.

² Carers NSW estimate based on Deloitte Access Economics (2015) *The economic value of informal care in Australia in 2015*.

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INTRODUCTION

Many children and young people living in NSW help care for their parent, sibling, other relative or friend, but young carers are often not recognised and miss out on needed support. The Young Carer Research Project conducted between December 2019 and June 2020 aimed to gather new evidence on the support needs and experiences of young carers aged 16 to 25, who are generally under-represented in the biennial Carers NSW Carer Survey. This report identifies the key findings of this research, highlighting implications for policy and practice.

A secondary aim of the research project was to explore and test different methods for engaging with young carers in research and consultation opportunities, which has often proven to be a challenge for Carers NSW and our partners and stakeholders. These learnings will be captured in detail in a subsequent Young Carer Engagement Tool, yet to be published.

This report shares insights from young carers across a range of themes, including education, employment, service provision and relationships, embedding the young carer voice throughout. These insights will help to inform ongoing and future service provision, research and systemic advocacy conducted by Carers NSW and our partners and stakeholders.

Young carers are children and young people aged 25 years and under who provide unpaid care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Young carers can be, but are not always, the main provider of support (the primary carer).

According to the 2018 Survey of Disability, Ageing and Caring,³ there are approximately 83,700 young carers in NSW up to the age of 25 years. Of these young carers:

- More than one in ten (13.9%) are primary carers
- Approximately 50% identify as male and 50% as female
- More than one in five (21.5%) live in rural areas
- 5.1% speak a language other than English at home
- 2.9% were born in a non-English speaking country.

According to the 2016 Census, there are also approximately 20,600 Aboriginal and/or Torres Strait Islander carers aged 15+ in NSW.⁴

Every two years Carers NSW conducts a survey of carers – generally confined to carers in NSW, but in 2020 open to carers across Australia for the first time – to provide an evidence base that informs service design, service delivery and systemic advocacy for all carers. Young carers have consistently been underrepresented in the survey, with low response rates reflecting ongoing challenges experienced by many researchers in engaging young carer participants.

Many young carers do not identify as carers because they view the support they provide as an intrinsic part of their role as a spouse, daughter/son, parent, relative or friend. Many others are not identified because they, or the people around them, do not know what a young carer is, or because they are afraid of the implications of disclosing their family situation, which could lead to stigma or

³ Australian Bureau of Statistics (2019) *Survey of Ageing, Disability and Carers 2018*, TableBuilder Dataset. Canberra: Australian Government.

⁴ Australian Bureau of Statistics (2016) *National Aboriginal and Torres Strait Islander Social Survey, Australia, 2014–15*, Table 10.3. Canberra: Australian Government.

bullying, or raise questions around child protection.⁵ This can prevent young carers from accessing carer information and services,⁶ especially those in regional communities, from Aboriginal and Torres Strait Islander communities, and from culturally and linguistically diverse backgrounds who face other barriers to accessing information and support.

In addition to not actively identifying with the term 'young carer', many young carers report being excluded by health professionals and service providers from discussions about their family member's condition and treatment, even when the care they provide is critical to that person's wellbeing. This can be due to their age, and to restrictive conceptions regarding the presence of a single 'primary carer' that do not account for the sharing of care within a family or network. In particular, if a parent is the primary carer, young carers in the family may be overlooked.

A review of existing research literature (see Appendix I) and internal consultation with Carers NSW staff working with young carers, conducted in the scoping phase of this project, identified that young carers are often isolated and experience socio-economic disadvantage as a result of their caring responsibilities. However, they are often reluctant to disclose their caring responsibilities to others and commonly perceive their own needs and experiences as less important than those of the person they care for. These factors can make it more difficult for researchers and others to successfully engage with young carers.

When seeking to engage young carers in research, consultation and other activities and services, a lack of carer awareness, non-inclusive language, and non-youth friendly formats and promotional channels can also be key barriers. To young carers lacking the time to participate due to competing commitments associated with caring, education or employment, time consuming or complicated steps to participation can be a disincentive. Accessing a young carer audience can be further complicated by the need to go through service providers, parents or teachers due to ethical requirements associated with their age, or in order to reach hidden young carers.

Prior challenges experienced by Carers NSW, our partners and stakeholders in recruiting young carers to participate in research and consultation activities, as well as support services and programs, have highlighted the need to seek up to date information from young carers about the support they need, and also how they prefer to be engaged with. This project sought to investigate and trial different approaches to recruiting young carers, engaging young carers in the research design and seeking input and suggestions from research participants to inform future engagement methods.

⁵ Cass, B, Brennan, D, Thomson, C, Hill, T, Purcal, C, Hamilton, M, and Adamson, E (2011) *Young carers: Social policy impacts of the caring responsibilities of children and young adults*, Report prepared for ARC Linkage Partners, October 2011.

⁶ Hill et al. (2016, p. 50) cited in Centre for Carers Research (2018) *Carer Wellbeing and Supports: A review of the literature and directions for research*, Institute of Public Policy and Governance, University of Technology, Sydney, September 2018.

METHODOLOGY

This research employed qualitative research methods to explore the experiences and support needs of young carers aged 16 to 25 in NSW. It aimed to investigate the following research questions:

- What are the experiences of young carers (aged 16 to 25 in NSW) in regards to caring, study, work, participating in their community and accessing services?
- What are the support needs of young carers in regards to caring, study, work, participating in their community and accessing services?
- How can organisations, service providers and researchers more effectively engage young carers in research and consultation?

Project Advisory Group

The Young Carer Research Project Advisory Group was established to provide guidance and expertise on project design and implementation. The group performed the following roles to ensure the objectives and outcomes of the project were achieved:

- Advise on Young Carer Research Project Plan
- Advise on research design, including methods of recruitment, data collection and analysis
- Support promotion and recruitment of participants for research with young carers in members' networks as relevant
- Provide feedback regarding research conducted and subsequent findings and reporting
- Contribute to the development of an engagement tool drawing on project learnings

A list of Project Advisory Group members is included in Appendix III.

Ethics approval

The Project was included as a sub-study of the Carers NSW 2020 National Carer Survey (ID: 6233), and was approved by the Macquarie University Human Research Ethics Committee on 2 March 2020. Given the short-term nature of the project, it was not feasible to pursue approval through the State Education Research Applications Process (SERAP) to conduct research with NSW public schools, however this option was explored to inform future research activities. Consent from parents or guardians was sought for one participant under 18 years of age. See Appendix IV for selected research materials, including the Participant Information and Consent Form.

Research design

Data was collected via semi-structured interviews (by phone or using Zoom videoconferencing software), with the option of an online focus group. These data collection methods were selected

based on existing research⁷ involving children and young people in Australia and the advice of academics involved in carer research. Interviews and focus groups were recorded with participant permission, transcribed, and data stored securely. All participant names have been changed to pseudonyms.

It is important to note that significant changes were made to the project scope and research design as a result of social distancing restrictions in place due to the Coronavirus (COVID-19), which peaked in NSW during the key data collection period of April to May 2020. As a result of this complication, plans for a series of face-to-face, interactive focus groups with online engagement offered as a back up were replaced with the final, web based research design. Fortunately, the change of mode did not reduce uptake as anticipated.

Data collected from the interviews and focus group were analysed using grounded theory and thematic analysis. The first three interviews were analysed for emergent themes and informed subsequent data collection. Open coding was completed manually. Due to time constraints resulting from COVID-19 adjustments coupled with an unexpectedly high participant response, in-depth analysis completed during data collection was limited. However, Carers NSW intends to conduct further analysis on the rich, qualitative data collected within this project to inform future publications.

In order to highlight the emergent themes in more depth and elevate the voices of young carers, a series of case studies based on experiences of individual participants are included throughout the report and in Appendix II.

Participant recruitment

Given prior challenges with recruiting young carers for research and consultation purposes, the Project Advisory Group was conscious of the risk of over-researching or over-engaging the same, small pool of young carers already in contact with Carers NSW. Highly engaged young carers known to Carers NSW were invited to take part in the research, but other methods were also employed to broaden the project's reach.

Participants were recruited using a multi-tiered approach both local and state-wide, along with snowball sampling (participants were asked if they knew anyone else who may be interested in participating, to garner potential referrals from the networks of participants themselves). The following regions were targeted based on existing or potential relationships with carer aware services, universities, young carers, and population data of young carers, and in order to ensure a balance of both metropolitan and regional/rural perspectives.

- Greater Western Sydney (Fairfield/Liverpool to Penrith)
- Canterbury-Bankstown
- Sydney City
- Wollongong/Illawarra
- Nowra/Shoalhaven
- Hunter New England and Central Coast
- North Coast

⁷ Grace, R, Knight, J, Baird, K, Ng, J, Shier, H, Wise, S, Fattore, T, McClean, T, Bonser, G, Judd-Lam, S, and Kemp, L (2019) Where are the silences? A scoping review of child participatory research literature in the context of the Australian service system. *Children Australia*. <https://doi.org/10.1017/cha.2019.32>

Communication materials were written in plain English language and framed for youth audiences (see Appendix V) and a \$50 gift voucher was offered to all participants as an incentive to participation. Activities to promote the project and recruit participants included:

- Targeted promotion to young carers currently engaged with Carers NSW (e.g. Young Carer e-News article, via emails and word of mouth)
- Promotion to local and state-wide carer aware networks (e.g. Carers NSW Strategic Carers Action Network (SCAN), local health districts, services, and universities with active carer engagement)
- Promotion via personal and professional networks of Project Advisory Group members

Interviews were arranged with flexibility to accommodate the time, participation and caring needs of participants. Young carers aged 26 to 27 were also included as appropriate, recognising their prior lived experience as 'recently young carers'.

Including young carers

Meaningful inclusion of young people in the research process was a key principle embedded in the design and planning of this project. Seeking suggestions and support from young carers in recruiting participants was also seen as critical to the project's success. The following mechanisms aimed to incorporate and recognise the young carer voice throughout the project:

- Two young carers were appointed in a representative capacity to the Project Advisory Group
- Research participants were provided with the opportunity to review the transcript of their interview and extracts of the project report
- Research participants were offered acknowledgement in the final report and a Letter of Acknowledgement recognising their initiative in participating
- Use of grounded theory to enable young carer voices to inform and guide data collection and analysis
- Inclusion key quotes and case studies in report to highlight the voices of young carers and provide context for their lived experiences.

FINDINGS

Participant profile

This research project aimed to interview 10 to 15 participants with the expectation that uptake during COVID-19 may be lower than anticipated. In the end, a total 28 participants took part in an online/phone interview or online focus group. Table 1 provides an overview of participants. See Appendix VI for a description of the Carers NSW programs mentioned.

Table 1. Participant characteristics

Characteristics	Number of participants
Participation category	
Interview	25 ⁸
Focus group	3
Total	28
Type of participant	
Existing association with Carers NSW	
<i>Carers NSW Carer Representation Program</i>	4
<i>Carers NSW Young Carer Program</i>	12
<i>Carers NSW Carer Achievement Pathway Program</i>	3
External to Carers NSW	9
Gender	
Male	5
Female	23
Age (in years)	
17-19	9
20-22	11
23-25	7
26	1

⁸ Two siblings participated in a dual interview.

Geographic region	
Metropolitan Sydney	18
Large regional city in NSW	5
Regional NSW	5
Disability or health condition	
Yes	6
No	22
Cultural background	
Culturally and linguistically diverse (CALD)	15
Non-CALD background	13
Aboriginal and Torres Strait Islander background	
Aboriginal or Torres Strait Islander origin	3
Non-Indigenous	25

Caring as a young person

Participants were asked a range of questions about their experiences and support needs in regards to caring as a young person. The following section outlines key themes that emerged around being a young carer more broadly.

Caring as the norm

"It's even hard to articulate what I do day to day. Because it's quite normal if that makes sense?"

- Melina, female, aged 24, metropolitan Sydney

"I thought it was a small part of my day-to-day life. I didn't realise that there was a term for what I was doing."

- Jack, male, aged 19, regional NSW

Most participants described caring as a normal and often unnoticed or unnamed part of their life. This was particularly the case for those who had been caring since primary school and therefore had cared for a loved one for over a decade. Some participants mentioned providing minor forms of help as a child and progressing to "more hands on" duties as they got older.

Participants described a variety of caring tasks that they performed, including housework, shopping, paying bills, looking after siblings, driving or going to appointments, personal care, and emotional support. Some young carers from culturally and linguistically diverse backgrounds mentioned

translating for a family member who did not speak English and speaking with utility providers to pay bills on their behalf.

The key point in time when participants realised they were providing care was often when they:

- came into contact with a young carer group, program or support, or
- compared their own life experiences with their peers.

Some participants realised they were carers due to specific incidents that led to the increased need to provide care.

"...When I was maybe 10 or 11, that's when I got in contact with a young carers group...And it wasn't until then that I thought, "Oh, maybe the stuff that I'm doing is a little bit more than everyone else is doing." And I think even realising, "Oh well, I can do the laundry and I know how to wash the dishes." But my friends don't know how to do their own laundry and they don't know how to clean the house. So stuff like that as I was growing up, made me realise that I was doing a little bit more."

- Amy, female, aged 18, regional NSW

Balancing caring with social activities

Participants were asked about their experiences balancing caring with their social life or extra-curricular activities, including time spent with friends and family, or talking to others about their caring role. Many were engaged in multiple activities including study, work, and community activities such as volunteering or sport. A small number of participants mentioned sport as their means of socialising and maintaining friendship groups. Others were passionate about social causes which also complemented their caring roles, including active participation with the Young Carer Program at Carers NSW.

"So aside from Young Carers I'm also volunteering at a nursing home."

- Natalie, female, aged 19, regional NSW

Some participants did not necessarily feel that being a carer impacted their social life and had been able to maintain friendships over the years. Others mentioned challenges such as cancelling plans due to unexpected caring responsibilities or limited time, and not being able to invite friends over growing up. Most participants described the need to be very organised and plan ahead to participate in extracurricular activities or socialise.

"Me being a young carer has shaped my social life a lot, because there's been times when I've said yes to going out to social outings, but then I've had to cancel at the last minute because mum's required my care. So that's obviously impacted on my social and emotional well-being."

- Jack, male, aged 19, regional NSW

While participants shared various experiences of caring and engaging in social activities, most described making deliberate decisions that established clear boundaries between their caring role at home and other aspects of their life.

Boundaries between home life and public life

Many participants mentioned keeping their caring role at home separate from other parts of their life, such as school, work and social life. Sometimes this was out of respect for the privacy of their care recipient and other family members, for others caring was normalised as intrinsic to their role at home and did not warrant speaking about in public.

“One of my best friends is the best, she says that I kind of put on a persona because to a lot of people who don't know me that well, I'm very much an extrovert, but, when it comes to certain topics, I'm definitely an introvert and I don't like to deeply discuss it... I also use that persona to kind of manage that and help me deal with it in a way that... I feel like if I do talk about stuff, I'd feel quite exposed, and so I try and shy away from talking about anything to do with my caring role.”

- Arya, female, aged 19, metropolitan Sydney

“I just don't really see the need to tell people I guess. It just kind of happens in my house, and it's just become a bit normal really, so I just don't really see the need. If people ask about it ... If they see mum walking, and they ask, then obviously I'd tell them. Yeah, but there's no real need to bring it up in my eyes. Yeah. I just get on with my life, I guess.”

- Hannah, female, aged 17, large regional city

Sharing caring experiences with friends

Many participants did not speak to friends about their caring role, and tended to avoid sharing with those who were not carers themselves. A small number were very open about their caring role with friends and work colleagues. Other participants sought informal support from close friends but remained private about their caring experiences elsewhere. Some participants mentioned feeling isolated and a lack of understanding from their friends when they tried to explain their vastly different experiences growing up.

Those who were connected with other young carers strongly valued these friendships for support and understanding. Ten of the 28 participants had been involved in the leadership development activities conducted by the Carers NSW Young Carer team, and many had stayed friends with other young carers who had participated. This group uses social media to stay connected and provides an informal support network to seek advice from other young carers of different ages.

“You know, we're in each other's lives, we were actually on it [group chat] last night from the Young Carer Leadership Program, which was about two years ago. But every now and again, particularly when things are going on, like the bush fires, or corona, we all try and get back in touch with each other. But I still follow everyone on Instagram as well. So we do keep in touch.”

- Natalie, female, aged 19, regional NSW

"I think it's really good because I'm able to get opinions and advice from people who are in similar circumstances. And I'm the youngest out of the group, so a lot of them have already been through the things that I'm going through, so that's good."

- Amy, female, aged 18, regional NSW

Participants who had not previously engaged with Carers NSW were less likely to be friends with other young carers. Some of these participants felt it would be valuable to meet other young carers, learn how they coped with their caring role, and hear stories about their lives.

"That's one of the things I found difficult. I don't know any other young people [who are carers]. And I think that would be nice... Something more casual though. I don't know if speaking about this all the time is wise."

- Nadi, female, aged 20, metropolitan Sydney

High self-efficacy and life skills

Most participants displayed a high self-efficacy, describing many occasions when they overcame challenges and believed in their ability to achieve goals while caring for a family member. Many participants mentioned life skills or attributes they gained through caring. Many participants felt they were more mature than peers due to their caring roles and having significantly more responsibilities. The skills and experiences that participants have gained have in turn helped them to manage caring alongside other aspects of their lives. Participants mentioned skills and attributes such as:

- Patience
- Empathy
- Resilience
- Being highly organised
- Time management
- Confidence in public speaking
- Skills relevant to professional fields
- Advocacy e.g. advocating for young carers and/or disability rights

"I've learned to be patient. I think that's a big one ... Just to not stress about getting everything done, and just to be a bit patient that things will kind of come and work out at the right time ..."

It's challenging too, because sometimes if Dad's not here, you've got to step up a bit and help out with some other things. If I'm not here, my sister will take my jobs as well. It does get pretty annoying, because you're like, "Oh. This isn't what I'm meant to do. This isn't my job", but you've just got to step up and do it."

- Hannah, female, aged 17, large regional city

Caring and studying

Most participants mentioned performing caring duties during their time at school, with some having cared for a loved one since primary school. The majority of participants were studying in senior secondary school, TAFE or at university at the time of data collection, due to the 16-25 age range specified by the project.

Diverse experiences and impacts of caring during high school

Participants shared various experiences of engaging in high school while caring. Experiences differed due to a range of factors including individual capabilities, the level of their care recipient's needs, support from family in undertaking caring responsibilities and emphasis on education, as well as support from their school. Some participants mentioned strongly valuing education and working hard to maintain their studies alongside their caring duties:

"...I was always one who excelled at school, regardless of the situation around me. So I was just always a natural student. I didn't let home life and school life interfere, ne'er the two shall meet... So education was always a priority."

- Natalie, female, aged 19, regional NSW

"...in terms of coping with my academic study, the subject that I chose during that period in which Mum was receiving the treatments were subjects that I loved. So as a result, I was willing to stay up all night and study. I mean, it was something that was really fun... I thought, well, I need to be here with mum and I can't be at school, so why not bring my work with me and if I needed anything, I could access the Wi-Fi that was there."

- Daria, female, aged 22, metropolitan Sydney

Some participants did not necessarily feel being a carer impacted on their schooling, and on reflection attributed this to supportive parents who prioritised their education. Others were providing care alongside other family members who were the primary carers, which made it easier to manage their studies.

"I think my mum has been such a big supporter for me in terms of my career and my education. It's something that she really prioritised for me, and I think she went through a lot of personal sacrifices to make sure that I had the time to do whatever I needed..."

- Sally, female, aged 19, metropolitan Sydney

"My parents have always been really good with education and they've always supported it so it's [caring] never really kind of affected that... Sometimes I've got to put that first and it means that I can't study or I have to work from home, but other than that we've got a really good team at home. So the family unit is made up of myself, my mum, my dad, and I've got another sister who also helps with the care. So we all kind of work together to make sure everything gets taken care of."

- Simona, female, aged 25, metropolitan Sydney

One participant mentioned attending schools that understood his needs as a young carer, providing flexibility to manage class attendance and caring for his mother.

"I was lucky enough to only live a short walk from my primary school. So there were times when I was in primary school, and both high school, that I needed to leave home to deal with emergencies that arose at home. So there'll be times when Mum might ring up the school and say, "Hey, I need Jack to come home." ...There are times when I needed to take days off from school. But yeah, both primary and secondary schools were amazing and understanding about my situation."

- Jack, male, aged 19, regional NSW

Conversely, participants who had significant caring responsibilities with minimal support mentioned increased challenges to their studies. Some participants mentioned missing days of school, others expressed worrying about their loved one's well-being while at school. One participant mentioned that her mother's condition worsened while she was at school, which led her to provide more care at home and reduce attendance during Year 11. The emotional toll impacted her so much that she *"just wanted to care for her and take care of her"*, and as a result did not continue her Year 12 studies. It was through the Carers NSW Young Carer Program that she was referred to the Carer Achievement Pathway Program at Carers NSW, which supported her to explore vocational qualifications while being a young carer.

Another participant, Larissa, had two young siblings to look after as well as care for her mother during high school. Her siblings were not able to help with caring during this period, yet she also protected them from having to take on caring responsibilities. This impacted on her ability to take on other opportunities as a young person:

"...going through school I struggled with [caring responsibilities] a lot more because the kids were so young. So, a lot of it fell onto me and only me... I've had to deal with a lot growing up and a lot with Mum... I didn't want the kids to have the childhood that I did, I wanted them to be able to do everything that they wanted to do and have all those opportunities and not have to turn down things..."

- Larissa, female, aged 20, large regional city

Tertiary education environments

Some participants felt engaging in studies after secondary school, such as university, was in some ways easier to manage with their caring responsibility. While young carers felt it was *"tricky"* to fit studying around caring, tertiary studies was overall seen as more manageable if they were organised early. In particular, many participants noted the ability to organise one's schedule based on available lectures and tutorials (e.g. booking all classes on the same day to reduce time at university and allowing more time at home).

A small number of participants mentioned the flexible nature of online education, although this did have its drawbacks. Most participants who were studying at university at the time of the interview had also moved to online learning due to the COVID-19 restrictions and had quickly adapted to using online platforms such as Zoom. While some participants valued this flexibility, for others the mandatory lockdown during the COVID-19 pandemic also meant a lack of respite for family members and care recipients, lack of alternative environments to study, emotional distress for care recipients, or increased caring duties to manage alongside studying. This was particularly challenging for participants with a larger caring role and minimal support from other family members.

“Studying has been easier and harder. It has been easier as I am home and can spend the day on education without needing to worry about work etc. But it is harder in that I wanted to study a bachelor degree on campus but could not leave mum to do so. Online education has meant I can become educated even though it was not my preference of courses.”

- Mandy, female, aged 22, large regional city

“And even the libraries are closed [due to COVID-19], so I can’t really use that as a place to go... That was the only way I was getting work done.”

- Nadi, female, aged 20, metropolitan Sydney

Support during studies

Support during education included reasonable adjustments such as provisions for the Higher School Certificate (HSC), assignment extensions, or flexibility in school or work attendance. Some participants had accessed financial support to assist with studies or living expenses. One participant was referred to the Young Carer Bursary Program through their university for financial assistance.

“...it’s about finding out what is out there that can help support your caring role... So one of the options is online study. The other one is you can access care support through universities, things like that. So it’s once you know what’s out there, once you’ve done your research, you know what your situation is, you know what you want and you surround yourself with the support that you need to be able to achieve what you want to achieve, then the rest just kind of falls into place.”

- Simona, female, aged 25, metropolitan Sydney

“Receiving a carer’s scholarship has really motivated me...The university has provided special consideration multiple times when I have provided evidence of my problem and they have allowed me to complete exams online.”

- Mandy, female, aged 22, large regional city

Some participants had not identified the impacts of being a young carer when they were at school and as such did not seek support, while others were sceptical of support such as school counselling. Many were not aware of available support throughout their childhood and adolescence. Participants shared a range of positive and negative experiences when they accessed support during their school years.

“...There was two counsellors I saw over the course of Year 11 and Year 12... They both supported me in accessing provisions for my HSC. That was really important. And I saw them on a regular basis. It was just, I remember it making me feel like I had a problem that other students just couldn't relate to in high school. Whether or not that was actually the case, I don't know. I don't know if there were other caring students in my high school that were accessing support.”

- Rebecca, female, aged 24, metropolitan Sydney

“I think my maths teacher ... was the first person who I told because he was a bit already like, "Why isn't she getting her homework done? Why isn't she able to get this done on time?" And then when I explained it, he was a bit more lenient and understanding and was able to give me a bit more flexibility, which was really helpful. And then the other teachers, they've just been really good to have a chat to and get their ideas on what to do [at home].”

- Amy, female, aged 18, regional NSW

Some participants felt a lack of carer specific support at TAFE or university. Some participants also expressed concern about a lack of understanding from or being judged by staff.

“In terms of my caring role, my university unfortunately is not the greatest at it. There's not really any provision, only recently because of the COVID situation, has there been anything available...”

- Arya, female, aged 19, metropolitan Sydney

“I didn't access [university support services] because I was just fearful of what that could mean for me. I was just worried would I be seen in a different light, how would that change the way I'm marked or assessed and stuff. And I just never accessed it.”

- Melina, female, aged 24, metropolitan Sydney

Caring and working

Some participants were working in casual, part-time or full-time roles at the time of their participation. A small number of participants had recently been working but their main employment had ceased as a result of COVID-19. The following themes were identified in relation to caring and working.

Transferable skills from caring to working

Many participants were able to identify skills and experience from their caring roles that directly related to their professions. In addition to the general life skills mentioned above, participants described other skills and knowledge gained through being a carer that translated to their studies or work in person-centred care sectors. Some participants had obtained employment that was strongly

informed by their caring experience, with one participant gaining employment supporting other carers after being a former client of the service.

"I have so much lived experience as a carer, and with exposure to different [health] conditions... I'm really excited for my future career, and it's really set me up with a lot of skills."

- Helen, female, aged 24, metropolitan Sydney

"...I have an understanding from a young age that it's actually helped me a lot, and even that personal experience, I work in child protection at the moment, so I guess a lot of the time there is young carers in the home caring for their siblings, or caring for their parent or everyone... I've been able to have some understanding of their experience which has helped a lot in terms of building rapport with them and things like that."

- Melina, female, aged 24, metropolitan Sydney

While some participants felt their caring experience was applicable to their professional lives, two participants studying social work were hesitant entering certain fields due to adverse caring experiences. This influenced their decision making around their future careers, choosing not to enter certain fields to take care of their own health or wellbeing.

"I think there's a direct correlation with the fields I'm studying and I'm working in with my duties at home. But... mental health now isn't a field that I would want to go to in the future because of those experiences, and not necessarily knowing how to support myself through that..."

- Nadi, female, aged 20, metropolitan Sydney

"I don't know if I want to go into mental health in the future in social work, only because I may find it too triggering for me. And I need to have that awareness now that can help me direct my future career. And I think maybe that's why I also go down the route of law as well, that other avenue that social work can be utilised."

- Helen, female, aged 24, metropolitan Sydney

One participant also flagged the potential negative impact of caring as an employee. Daria was completing her university studies in psychology and had not been able to obtain work experience due to caring for her mother, looking after her siblings, volunteering and studying. She expressed concerns about how this may impact her future job prospects:

"...One of the major concerns that I have is once I can work, if I can, how am I going to explain to the employees that I have no really employee history and I've never really performed any formal work? I do have these five things that I do with volunteering and it's prepared me with all these skillsets, but I have so much skills as a carer and I don't believe that's really recognised in the workforce..."

- Daria, female, aged 18, large regional city

Working in community services

Participants who worked in human or community services mentioned that their field of work led to them having managers, colleagues and workplaces that were understanding of their caring role. As a result, many participants were able to access flexible working arrangements on an informal basis, for instance being able to work non-standard hours to care for a family member.

"...my boss at the moment she's really good. She's always aware of my home circumstances. So she's always very open... if I had to go leave early to pick [care recipient] up or had to take the day off just to look after him. Every workplace I've been to has been really accepting of that."

- Alison, female, aged 24, metropolitan Sydney

Working in a community services related field did not necessarily lead to participants seeking support, but for some the workplace was a context that offered informal support. For instance, one participant was a social worker and mental health carer for both of her parents. When she disclosed her caring role to work colleagues they validated her experiences and provided emotional support.

"...I was getting calls from my parents at work. So I started to talk about it [caring role] a little bit more with my co-workers... they commended my work and stuff like that, as well as having everything else happening at the same time. So I think that affirmed to me that it's [caring] actually a strength not something that isn't. And I sort of already knew that, but I guess when you hear it, it makes a difference..."

They were heaps good, and always curious about what my life looked like... Sometimes we'd laugh about the funny things that go on when you're caring ... and that just would lighten what's happening."

- Melina, female, aged 24, metropolitan Sydney

Managing jobs to manage caring role

A small number of participants expressed challenges with obtaining casual or part-time employment while caring. This was sometimes negotiated within the household between siblings or family members. For example, Samantha and Larissa took part in a dual interview. They shared the challenges with coordinating their work schedule depending on their caring responsibilities and who is available to care for their mother.

"And it's hard for us to get a normal, regular, everyday job because we're expected to do so much at home."

- Larissa, (Samantha's sister) female, aged 20, large regional city

"I am not able to work at all unless my sister is home and because she works full time this means I can only work weekends. I also cannot leave Mum until about lunch time each day so if I want to work Saturday and Sunday afternoons are my only option."

- Samantha, (Larissa's sister) female, aged 18, large regional city

While some participants felt their workplaces were supportive of their caring role, a small number of participants in employment mentioned stress associated with managing work and caring. This included maintaining household duties at home, negotiating flexible arrangements, and emotional stress such as worrying about their loved ones while at work.

“...This is something I’m struggling with my workplace as well, it’s like flexible working arrangement is tricky to even ask for... I’m a casual officer... I would have loved to take full time work, or part time work, but unfortunately I can’t because they’re not flexible with the hours, the days that I need.”

- Jin, male, aged 26, metropolitan Sydney

“...I’ve just got into a new position, in a higher role, and you want to do the best in your position. And I’m 25, so I’m learning new things. I’m growing, all that kind of stuff, but ... when my pop’s unwell one day, and my nan isn’t feeling the greatest, I feel like I need to stay home and support them. But, no, I need to go to work. It’s just really hard like that.”

- Danielle, female, aged 25, metropolitan Sydney

Disclosing a caring role at work

Most of the participants who had been employed tended to disclose their caring role on an ‘as needed’ basis. For example, some participants mentioned caring when they needed to take time off work or negotiate alternative arrangements for caring responsibilities. A small number of participants were open about being a young carer to colleagues. Some, but not all, participants who had been involved in leadership development activities conducted by the Carers NSW Young Carer Team also included this in their resume. Participants who shared they were a young carer in job applications recognised the relevance of their caring role to broader employment. Some participants had also had positive discussions with workplaces that supported their caring role as a result.

“So when I first started [work], I put it on my resume that I was a young carer, and they’ve always been very accepting of it. I know that if I had to take some time off to do something in an afternoon, they’re fine with it, which is good.”

- Katie, female, aged 21, regional NSW

“I did put it in my resume because I did a lot of community work with Carers NSW...I think it’s good to add it. I think it’s like that idea of community engagement and expressing that you have something of interest.”

- Stacey, female, aged 21, metropolitan Sydney

The following case study outlines the experience of one participant whose workplace had a limited awareness of caring and the carer role. It highlights the key role that employers play in supporting or hindering young carers to manage caring and their own well-being.

Case study: Caring while working

Danielle* is a young Aboriginal woman from metropolitan Sydney. She is 25 years old, working full time, and helps her grandmother in caring for her grandfather who has dementia and a physical disability.

Generally, Danielle felt managers were “pretty good” about her caring role. However, on one occasion they had to place her grandfather in a nursing home, as it was the only way her grandmother could get respite. Danielle had started a job and could not take leave immediately. Usually she would care for her grandfather every day after work, but during the COVID-19 pandemic, visiting hours at the nursing home were restricted to the middle of the day:

“I just asked if I could go, a half an hour lunch break, hour and a half leave, and it was basically, this massive issue and they said no... I felt like I was being attacked and I had to justify why I was seeing my grandfather. And that really got to me... I felt like I had to justify my relationship to my grandfather... I already provided enough information.”

After the situation was addressed and she was able to work flexibly, Danielle felt it came down to “things being lost in translation.” Would it have been different if it was her child rather than her grandparent? While co-workers said they were understanding and supportive, Danielle felt their “actions are just telling me otherwise”.

Being able to take leave and allocated days off has been key for Danielle to provide care so her grandmother can have time for herself. She recognises the impact of caring full-time on her grandmother, and continues to manage her work so she can help care her grandfather:

“So it’s like I’m looking after my pop, but I’m also mindful of my nan. She does this every single day, I can’t imagine. It’s extremely hard work, not just physically, but emotionally as well.”

*Pseudonym used.

Accessing support or services

All participants were asked if they had ever thought about or sought support for themselves as a carer. In general, the supports and services participants referred to were those offered specifically within educational and employment environments, rather than community services contexts.

Some participants who had performed caring tasks as children had accessed support organised by their parents or were referred to support by a service provider of the person they cared for, such as a support group for siblings of children with a disability, young carer programs, respite activities, or counselling. These participants had often been connected with carer support and services for a number of years. For instance, Katie was referred to a siblings group in primary school, and had since engaged in various carer related programs:

"I first heard of the term young carers when I was in primary school. The company that my brother went through for physical therapy and occupational therapy, they started a siblings group..."

- Katie, female, aged 21, regional NSW

"The regional carers group was through one of my sister's service providers... I kind of grew up with that and did a lot with them... That young carer group got me connected to the Carers NSW...and then it kind of evolved from there..."

- Arya, female, aged 19, metropolitan Sydney

Some participants had approached their GP for a mental health plan as young adults during challenging periods and accessed counselling. A small number of participants mentioned limited programs and support for young people at different ages. For example, some participants had accessed respite activities and programs during primary school and high school, but there were limited options for young people aged 18 years and over. One participant mentioned being part of a carer support group, but that the demographic was usually adults aged 40+.

Counselling was the most common form of support accessed by participants throughout their life course. Participants who shared positive experiences mentioned traits such as empathy, understanding, and having a comfortable setting. Participants with negative experiences mentioned counsellors who did not understand their caring situation or the needs of their care recipient, a lack of culturally sensitive services, inconsistent staffing, or services being booked out.

"Yeah, so the experiences that I've found with counselling are really good. The counsellor listens. The counsellor understands. They'll show empathy. And yeah, they've provided me with tips and advice... Yeah, I found it really beneficial."

- Jack, male, aged 19, regional NSW

Reasons for not accessing services

While many participants had engaged support for their caring role, some participants had not accessed services or support for themselves. This study included many participants from culturally and linguistically diverse backgrounds (n=15). Some of these participants felt that there is a lack of culturally appropriate services for care recipients and carers. This impacted on some of their experiences accessing support, and risked deterring them from seeking further support in future.

"I don't really see much diversity when it comes to our services. In terms of representation and culturally and linguistically diverse peoples. Everyone that I spoke to was not of a similar culture and wasn't able to relate or made a lot of assumptions about how the family household was being run."

- Nadi, female, aged 20, metropolitan Sydney

Some participants identified challenges with caring that affected their health and well-being but chose not to seek formal support. These participants had varying degrees of caring responsibilities from being the primary carer to sharing caring with multiple family members. Some participants tended to self-manage their mental health through the life skills they have developed, and doing activities such as physical exercise or going for a walk.

"I've thought about it, but then ... I don't know. I just kind of haven't really followed through, I guess. I don't know. It's usually when it's just a bad day, and then the next day it might be better, so I'm like, "Okay. It's all fine again. I'll just keep going." Yeah. I've never really reached out to anybody. I just kind of dealt with it."

- Hannah, female, aged 17, large regional city

DISCUSSION AND ANALYSIS

Carer identification vs. carer identity

The findings of this research highlight an ongoing tension between a young person's need to adopt the carer identification to access support, while not necessarily identifying with the term 'young carer'. Participants saw caring as a "normal" part of who they were, and many did not see the need to publicly disclose this aspect of their life. This was sometimes in response to stigma surrounding the care recipient's condition and the need to care for a family member. Some participants held very high expectations of themselves and did not want caring to impinge on their ability to lead meaningful productive lives.

"...when I hear the word "carer", I don't know, it just makes me – I don't know. I just have this whole stigma attached to that word."

- Danielle, female, aged 25, metropolitan Sydney

At the same time, most participants recognised that young carers have unique life experiences distinct from their peers, and the challenges that can accompany caring requires nuanced understanding, attention and support. Many also recognised the skills and experience they gained from caring as a strength. Some participants used carer identification as a tool to access support without adopting the carer label in their own identity as a young person.

"It was very life changing the first moment I received the [carer] payment. So I remember that the whole process was quite complex and ... I find it very difficult to suddenly sit with somebody that I've never met, don't know and then tell them in detailed form what I do... It was very hard, but the first payment check I received was significant, and it kind of gave me emotional gratification that, "Oh, wow, somebody really recognises what I do and they pay me for it?"

- Daria, female, aged 22, metropolitan Sydney

Conversely, many of the participants who were either Carers NSW Carer Representatives or had been involved in leadership development activities conducted by the Carers NSW Young Carer Team had embraced the young carer identity as a platform to advocate for other young carers, such as by raising awareness in their local schools, participating in consultations, or speaking to the media. Some of these participants expressed pride in sharing their story as a young carer. Participants who had engaged with these programs or other carer support groups, particularly from a young age, had greater access to carer networks. Given the importance of understanding and empathy towards caring experiences, these participants had been able to foster meaningful friendships with other young carers and rely on them for emotional support.

"My advice is that, give yourself the title of a young carer even though that maybe some other people in your life might not want to accept it, that you are, but [it] gives you access to support services that are only available to young carers. And you can connect with ... other people that are in similar situations to you. Just don't be afraid to open up and speak out."

- Jack, male, aged 19, regional NSW

Mediated access to services and support

The findings highlighted the key role that adult figures can play as mediators or facilitators for young carers in accessing support. Referrals from a perceptive, understanding, and carer aware adult within the family, at school or university, or from the care recipient's service provider facilitated uptake of support by the young carer themselves. When employers and managers took care in responding to participant requests, young carers were able to participate in paid work alongside their caring responsibilities. Many of these interactions were only able to take place because the young carer experienced a level of acceptance and understanding of their circumstances, and did not feel judged or stigmatised.

Some participants had been connected with services and support since primary school, usually before they realised they were providing care, and often by a carer aware parent or service provider for the care recipient. This equipped some participants with a level of carer awareness from an earlier age even if they did not have the language to articulate their role. It also enabled a sense of trust in services and programs aimed at young carers.

Conversely, many of the participants who were not connected with Carers NSW had not accessed formal support for their caring role. Some had been caring for many years with varying degrees of support from other family members and service providers. One participant had a poor experience with a counsellor and after challenges accessing the service, stopped seeking support and has been hesitant to try again. These examples highlight that the ways in which adults and institutions engage young carers are of vital importance.

Key example: Caring during school years

The case study over the page highlights how a trustworthy and understanding teacher supported Arya to manage caring and education during high school.

Case study: Caring during school years

Arya is 19 years old from metropolitan Sydney. She cares for her older sister with varying disabilities alongside her parents who are the primary carers. Her caring role ranges from emotional support to cooking, cleaning, personal hygiene, and more recently transport.

As a private person, Arya didn't talk to many people about her caring role; her friends and teachers thought her need to be extremely organised was just part of her personality. During high school, sometimes she would be tired from taking care of her sister, or struggled with homework. Most teachers just thought she wasn't able to sleep well, but one teacher, "*somehow figured out there was something different*" and approached Arya. She could see this teacher "really cared", which allowed Arya to open up about caring for her sister:

I had that particular teacher for ... five years, in my six years of high school, and it was more like, she would just check up on me. After class, she would be like, just hang out for five minutes ... [and check] how's everything going. And if I was struggling, she'll help me work through it.

...Also, when I revealed it to the rest of the teachers, she kind of took charge and helped me figure out exactly what I could get from each of those teachers without having to expose any more of myself... which was nice, because then I didn't have to continually repeat my story to everyone.

Arya's teacher helped provide leeway around homework and assignments when she needed support, respected her privacy, and did not judge Arya because she was a young carer. This trusting relationship made a positive impact throughout Arya's time at school:

"...I think she was probably the first and only instance where I opened up to kind of someone who wasn't a friend necessarily, someone who was a figure, an authority figure... I graduated nearly two years ago, and I still keep in contact with her because she now knows who I am."

Facilitators of engagement

The findings from this research highlighted several key factors that assisted young carers to access with services or support. Learnings from the research process also supported these findings by providing insights to how future engagement with young carers for research and consultation purposes could be more effective. A summary of the key enablers and barriers to engagement identified in the project is included in Appendix VII.

Trustworthy and supportive interactions

The findings emphasised the importance of positive interpersonal interactions when identifying and encouraging a young carer to seek support, as well as when a participant actively sought support for their caring role. This was particularly key when young carers were experiencing heightened stress or in a period of crisis.

In the data collection phase of this project, interviewers were responsible for 'holding space' that allowed participants to share experiences as a young carer. For some participants, it was the first time they had reflected on their own experience with a 'young carer lens' or sharing certain stories considered private. Some of the experiences shared were distressing or challenging for the participant, which required the interviewer to apply skills in accidental counselling, empathy, and appropriate referral. Support provided included accidental counselling during the interview and soft referrals to the Young Carer Team for debrief. Navigating the emotional well-being of participants alongside asking questions to collect data was crucial to maintain trust and safety.

Overall, participants who had their young carer role validated, accepted and understood by others through empathetic interactions, were able to engage with valuable support, programs, and networks for carers.

Carer aware educational institutions, services, and workplaces

There were various settings that young carers navigated on a regular basis and which provided opportunities to access support. Settings where there were people who understood participants' caring needs were able to provide or refer them on to relevant support. For instance, participants mentioned learning about carer specific support through public health services and general practitioners (GPs). Working in human and community services provided some participants with networks to managers and colleagues who were understanding of their caring role. These employers were able to accommodate for varying caring experiences, including circumstances that were irregular or during stressful situations for the participants.

The recruitment phase of this project also targeted carer aware university lecturers, Local Health Districts, and service providers (e.g. disability, mental health, physiotherapy etc.) who were able to engage hidden young carers who had not yet engaged with Carers NSW. Two universities were able to promote the project to registered student carers because they had carer specific provisions available and an existing system of identifying student carers.

Connecting with other young carers

Most participants, whether they were active in carer networks or did not identify as a young carer, expressed the importance of meeting other young carers and hearing their stories. This strengthened their carer awareness and understanding of their own experiences as caring. It also increased some

participants' networks with other young carers, which served as valuable informal support, connection, and sense of belonging. Participants who were connected with other young carers were also more likely to have accessed formal support services.

Some participants who had not previously engaged with Carers NSW did not necessarily identify as carers, but expressed interest in this research project because they wanted to contribute their experiences to help other young people who provided care.

"It's actually good to get some stories out there, because I think – for example, for me, as an Aboriginal person ... I'm caring for my Pop... It's like a cultural responsibility, this is just what you do."

- Danielle, female, aged 25, metropolitan Sydney

Key example: Young carer networks

Informal and formal structures to connect young carers with each other can help increase access to carer-related support. The case study over the page shares how one young carer worked with his teachers to establish a young carer group at his high school. It highlights the importance of providing safe spaces to share young carer experiences, having supportive staff to manage duty of care, while also allowing initiatives to be young carer and student led.

Case study: Young carer networks

Jack is a 19 year old young carer from regional NSW. He has been caring for his mother who has lived with mental health issues, depression, anxiety, and panic attacks since about the age of five. He completes household duties such as cooking and cleaning, along with arranging and attending medical appointments. Jack has strong connections with carer support, having been involved with the Carers NSW Young Carer program for many years, as well as local services.

In high school, Jack started a young carer club with the help of the Head Teacher Welfare and his Year Advisor. He felt it was important “having good friends that you can talk to”, including those with shared experiences of caring. The group met at lunchtime and had one session each week for about a year:

“So we started off by bringing in some snacks, by playing some board games, by sharing with people who wanted to share... I still remember to this day some young carers in the room saying, “There’s some people in this room, in my year, that I didn’t even realise were a young carer.”

The club catered for students from low socio-economic backgrounds, provided free or low-cost activities, and was an informal space that focused on students’ interests. It also helped that Jack was well-known in the school community, and took the lead and initiative to connect with other students.

Organising a formal group had its challenges, “because there’s all the paperwork ... that needs to be sorted out”, but some supportive teachers helped him set up the group. They were also available for referrals and duty of care:

“...I’m lucky I had the support of the Head Teacher Welfare and my Year Advisor. And I was able to debrief with them afterwards, if anything did become a bit too much now. I did see the counsellor maybe once or twice there at the school just to talk about what was going on, as well. But after about three sessions, I learned to not take it in as much.

“...They [staff] were there for maybe the first two or three sessions to supervise, and then after that, they were just in a room nearby. And if somebody wanted to talk, and they didn’t feel comfortable talking to me, they could go to ... the Head Teacher of Welfare, or the Year Advisor.”

Jack felt the club made a “huge difference” because it provided a space for “that common understanding” where other students may not be able to understand the carer experience:

“...a few of them even broke up in tears when they were telling their stories, ‘cause they said, “This is really the first time I’ve been able to connect with other people that are in similar situations to what I am.” So really, made a big impact. And I said, “This is my respite. My self-care, just going away for an hour or two, just forgetting about what’s going on.””

Approximately 30 young carers were involved with the club at the one school. Connecting with other young carers increased Jack’s understanding of his own mental health, and social and emotional well-being.

Accessing digital information

It was clear that the high self-efficacy of participants enabled them to balance different aspects of their life with caring. The findings revealed that many participants were proactive in doing their own research online and accessed information that would help their caring role.

"I've found a lot of information through my local headspace centre, because their target age group is 12 to 25. And yeah, basically online, whether it be through our Facebook pages, whether it be through adverts that pop up on YouTube, anything online, apps that you can download from the App Store, preferably free, if that's an option. And just speaking to health professionals."

- Jack, male, aged 19, inner regional

Some participants mentioned using social media to both access information and connect with other young carers (e.g. Facebook and Facebook Messenger). Online messaging platforms afforded a level of flexibility that suited young carers' often busy and changing schedules.

"A lot of people can just quickly pop in for five minutes and talk and say hello... It's quite convenient in that regard..."

- Arya, female, aged 19, metropolitan Sydney

Some participants found out about services through face-to-face avenues, such as posters at university, community spaces, or seeing their doctors. Some participants mentioned the potential for promoting information through local youth centres such as PCYC and headspace.

Inclusive language for young people

Many participants noted the importance of language used to engage young carers in carer support, research or when interacting with their care recipient's service providers. Given the tension with the term 'young carer' for accessing services versus self-identifying, inclusive language that is jargon free can help facilitate engagement. One participant did not identify as a carer but when they read the promotional flyer for this research and moved past the 'young carer' label, they saw themselves in the description of caring tasks.

Other participants emphasised the need to provide information that was accessible for their understanding. For many participants who cared for a family member with complex health conditions or disabilities, they expressed the need for service providers to include them in conversations but also communicate with them in a way that they could understand without the technical knowledge. One participant mentioned that the language used and information provided needs to suit different ages, including for children who are carers.

"...having language that's easy to read for an eight, nine-year-old, having a lot of pictures as well helped a lot... [NSW] Health like to use jargon a lot and acronyms; not using acronyms or if they are using acronyms telling me what they stand for helps a lot. And ... not being judgmental as well in regards to my caring journey."

- Jack, male, aged 19, regional NSW

Barriers to engagement

Lack of carer awareness

Many participants who experienced negative interactions as a young carer highlighted a lack of empathy and understanding from staff in schools, health services, or workplaces. These individuals in positions of influence did not understand their caring role and its impact on their wellbeing, studies, or capacity to participate in employment. Some participants were concerned that general services within education (e.g. student welfare), or services that were not specific to their care recipient's condition would not understand the complexities of their family situation. The following case study highlights how a young carer's behaviour can be misconstrued when those providing support have minimal awareness of caring:

Case study: Caring during school years

Melina is 24 years old from metropolitan Sydney. She cares for both parents, including for her dad with a mental health diagnosis. During high school Melina felt the need to hide her parents' condition: *"I was always sort of ashamed and embarrassed and always felt like maybe I'd be discredited because of it..."*

Melina was responsible for getting herself ready for school and often found it hard to make it on time. She attended a strict all-girls' school and her teachers were unaware of challenges faced by carers, so would often get her in trouble:

"...My uniform and things like that for school wouldn't be the best or I would wear a different uniform, and the teachers would get me in trouble, and it was the least of my worries... they were very strict about punctuality... I felt like I was always getting in trouble at school and then I had to go home and deal with more crap."

They referred Melina to the counsellor when she was 15 or 16 years old as they, *"saw that I was not really concentrating in class and I was a bit naughty here and there."* It was not until this point that more of her teachers were made aware of her situation. However, this resulted in a complete shift in the way that teachers treated her, which unfortunately did not feel supportive:

"...I remember being really upset because it was like they completely shifted because they now maybe pitied me... They always just thought I didn't want to follow the rules or come to school early and things like that. And they thought it was a deliberate choice, as opposed to when they knew what was happening and stuff, then they thought, "Oh okay. It's not really in her control." So they changed. But I wish that they had had that thinking prior towards any child."

When reflecting on how teachers could better support young people with caring responsibilities, Melina felt it was important to not assume that a student is purposefully trying to do the wrong thing: *"...I think they should try and work out what's underneath that behaviour, rather than just label that child or give them punishment."*

Lack of available information at school/educational institution

Many participants wished they had access to information about caring, support for carers, or knowledge about their care recipient's condition earlier, particularly during their early years of high school. Some participants felt they would have sought support for themselves earlier or would have felt less alone if they knew what services were available. Some felt unprepared to be a carer, while others were unsure how to support their family member with their disability or health condition without more information. These participants often wished there was a "handbook" to provide advice.

"There was not an education about carers, I wasn't really prepared for the stress... No one is prepared. My sister wasn't prepared to have a diagnosis, my parents weren't prepared to face the reality of having a sick child, I wasn't prepared for having the reality of having a sick sibling."

- Rebecca, female, aged 24, metropolitan Sydney

While all of the participants in this study had attended secondary schooling, only a small number had accessed information about caring at school. Some participants also noted the lack of information at different points of transition (e.g. starting or finishing school or tertiary education).

"...The end of high school ... is an important time for a lot of students. Having what services are available, how we could apply for considerations and bonus points and that sort of stuff would be nice to have known earlier, so I could not have rushed to do all that. Because I didn't find out until ... beginning of year 12."

- Arya, female, aged 19, metropolitan Sydney

Negative experiences with services

It was clear that negative experiences with services or when seeking support was a barrier for some young carers. Some participants mentioned service providers that did not recognise their caring role, did not understand their care recipient's condition, or were not culturally responsive. A small number of participants mentioned potential stigma attached to the notion of being a carer and as such did not seek support for themselves.

The case study over the page highlights how negative experiences while caring can be exacerbated across services and settings. A lack of cultural competence, stigma around mental health, and lack of understanding of young carers amongst service providers can significantly impact the well-being of young carers.

Case study: Accessing services

Nadi is a young Indian woman from metropolitan Sydney and is studying at university. She is 20 years old and has been providing care for her mother over the last decade. From a young age since they migrated to Australia, Nadi would help with English translation and filling out paperwork. As she got older, Nadi provided more mental health support including organising and attending meetings, and errands such as grocery shopping.

One night her mother experienced a severe mental health episode and no one else was home at the time. Nadi didn't know what to do, decided to call Kids Helpline but was unable to get through. She ended up calling the police who came and assessed the situation, put her mother under an involuntary treatment order, and took them to hospital.

The hospital staff did not recognise Nadi as a young carer, yet she had to communicate and translate for her mother as no translator was provided. At one point, Nadi was told to leave and wait in the waiting room.

"So, being a young carer in a hospital as well, I didn't feel like I had any support from staff or, yeah, I was very much looked down upon."

It was a very distressing experience and did not lead to further support for her family. This impacted Nadi's own health and wellbeing, so she saw the university counselling service but it did not meet her needs:

"I did see ... counselling and psychological support, at the university; and they ended up shaping it around how that might affect my studies, which I didn't understand. I was like, "I didn't come to you to talk about how it's affecting my studies, I came to you for support." ... I've just been told that is a short term service and they can't really do anything."

Soon after the incident took place, Nadi was studying a mental health unit for her degree. One assignment was specifically about involuntary treatment orders and Nadi was asked to present on this topic. Despite not feeling ready, Nadi's lecturer "didn't respect that" because of the opportunity for her peers to "hear about a lived experience perspective". The situation was not managed in a trauma informed way, as Nadi was not given the agency to decide whether it was the time to share her experience.

Despite these adverse experiences and minimal access to supportive services, her studies and casual work in the disability space have in many ways complemented Nadi's caring role:

"I find that work quite rewarding, and I am learning a lot about what my rights are... A lot of that work requires facilitating programs and activities. And whatever I implement there, I end up just implementing at home as well."

In terms of what could be improved to support young carers, Nadi believes it is important to have culturally and linguistically diverse people represented in services, to have the experiences of young carers validated, and that services follow up with meaningful support.

Lack of time

While participants ranged from being the primary carer to having several family members providing care, the majority mentioned time as a challenge to balancing aspects of their lives with caring. When the significant amounts of time is spent on caring, studies, or working, it can leave minimal time to access information, seek support or access services. Even when there was interest to seek support of reach other young carers, time was sometimes a barrier. For instance, one participant was involved in organising a carer network in their university, but was unable to continue due to her own study commitments, as well as minimal attendance by other student carers.

Some participants cared for a loved one with complex needs or a rare health condition, and found it challenging to describing their caring situation when seeking support. This included during times of crisis or facing unexpected circumstances. The barrier of time needs to be considered when engaging young carers.

CONCLUSION

The Young Carer Research Project aimed to gather new evidence on the support needs and experiences of young carers. This report canvassed a wide range of experiences shared by young carers across NSW. The findings highlighted caring as a normal part of young carers' lives and is negotiated across social activities, studies, and work. Participants were resourceful in navigating their caring role with an often high self-efficacy, applying valuable life skills gained through caring, and accessing support or services.

The diversity in experiences also highlighted the need for carer identification to access support as well as potential tension with adopting the carer identity. It showed that services for care recipients, educational institutions, and parents are key gateways for young carers to access support for themselves.

This report has provided insight into key facilitators and barriers to engagement that can inform education, employment, services, and research settings. The high participation for this study has also shown the possibilities of effective engagement with young carers, which will inform future research and practice. Recommendations and implementation activities will be further explored within Carers NSW and will inform the development of a Young Carer Engagement Tool to accompany this report.

Limitations

This project faced some limitations impacted by time constraints, major changes to data collection methods as a result of COVID-19, and an unexpectedly high participation rate. Targeted recruitment focused on participants already engaged with Carers NSW potentially reflects a narrower body of carer experience in the findings. Many participants were Carer Representatives or had been involved in leadership development activities conducted by the Carers NSW Young Carer Team, some of whom are very experienced in sharing their stories as young carers. Participants recruited through service systems and already engaged in carer services may have access to support that is not reflective of the experiences of hidden young carers.

Moreover, due to the qualitative nature of this research, the findings are not representative in a statistical sense of the broader population of young carers in NSW. Rather, this research provides in-depth insight into the experiences of a diverse range of young carers.

Implications for future research

Given the wealth of data that this project generated, there are many opportunities for future research to inform ongoing practice. These include the following topics:

- Emerging practice and policies for carer support provisions at universities
- Young carers in transition e.g. impact of caring on choice of work, future pathways
- Experiences of Aboriginal and Torres Strait Islander young carers
- How the young carer experience differs according to gender, cultural background, geographic location, and the types of health or disability of care recipients
- Carer identity versus identification and the impact on accessing and providing services

It should also be noted that, while the Project focused on those aged 16 – 25 for ethics purposes, children and young people under 16 years of age can also be carers, and the needs and experiences of younger young carers should be prioritised for future research.

APPENDICES

Appendix I: Summary of selected Australian young carer research

Project summary	Research methodology	Communication channels / promotion
<p><i>Carers, We See You: UTS Student Consultation Report</i></p> <p>This study explored the experiences of student carers at University of Technology Sydney (UTS).⁹</p>	<p>Student focus group discussions with five student carers from a diverse range of backgrounds.</p> <p>Focus group discussions with seven Academic Liaison Officers.</p>	<p>Internal networks and communication channels.</p>
<p><i>Supporting young people having a parent with Younger Onset Dementia (YOD)</i> by Dr Karen Hutchinson, Macquarie University (formerly University of Sydney)</p> <p>From PhD thesis: Exploring the experiences of whole families living with younger onset dementia: a social model perspective.</p> <p>This project explored the lived experiences of young people from the perspective of the social model of disability. It proposes a 'whole family' approach, "where the needs of young people and their parents are respected and responded to age appropriately."¹⁰</p>	<p>Semi-structured interviews with 17 purposely sampled participants.</p> <p>Most participants were aged between 19 and 33 years at the time of interview, plus one person aged 9-10.</p> <p>Interviews focused on participant experiences from the age of 8 to 24 years.</p> <p>Interviews were conducted with the participants in their homes, place of work or local library.</p> <p>Thematic analysis of recorded and transcribed interviews.</p>	<p>Advertised through Alzheimer's Australia NSW (now Dementia Australia) and Young Carers NSW (young carer networks).</p> <p>Found participants through support groups and psychologist.</p>
	<p>Collaborative workshop with 30 people including "representatives of government, general practice, aged care, researchers, youth mental health and support service providers in partnership with consumers, namely young people and their parents living with a diagnosis of YOD"¹¹.</p>	
<p><i>The ReSPECT project</i>, led by Dr Rebekah Grace, Western Sydney University</p> <p>This project aims to make the voices of young people heard on issues of social and health service provision. It employs a participatory approach, engaging children and teens in re-envisioning the service system and in developing and trialling child-led service initiatives.</p>	<p>Participatory research and inviting participants as researchers and "developing 2-3 initiatives they would like to see implemented within local services, based on their experiences and research, and pitching them to local service providers"¹².</p> <p>Peer led interviews with other young people in their communities.</p>	<p>Advertised through emails to networks, including Carers NSW and YCs, schools with established relationships, university website.</p> <p>Flyers.</p> <p>Offer of \$20 gift voucher per session attended.</p>

⁹ Svejkar, D, Gleeson, P and Viswanathan, P (2019) *Carers, we see you*, Centre for Carers Research, Institute of Public Policy and Governance, University of Technology Sydney.

¹⁰ Hutchinson, K, Roberts, C, Kurrle, S, and Daly, M (2016) The emotional wellbeing of young people having a parent with younger onset dementia. *Dementia*, 15(4), 609-628, doi:10.1177/147130121453211

¹¹ Hutchinson, K. (2014) *Report summary on a collaborative workshop 'Supporting young people having a parent with Younger Onset Dementia (YOD)'*. University of Sydney.

¹² Re-conceptualising services from the perspectives of young people (ARC Linkage project LP170100570), CI: Rebekah Grace, Western Sydney University, 2019-2022.

<p>Supporting carers in higher education led by Lisa Andrewartha, Giovanna Szalkowicz and Associate Professor Andrew Harvey from La Trobe's Centre for Higher Education Equity and Diversity Research (CHEEDR), in partnership with Carers Australia (Victoria)</p> <p>La Trobe University launched a national research project in November 2019 to increase access, support and outcomes for carers studying at Australian universities.</p>	<p>Mixed methods approach.</p> <p>Currently collecting data via online survey, which covers topics such as: demographics; caring role; transition to university; university study; experience at university; and future plans.</p>	<p>Promotion through networks.</p> <p>University website.</p>
<p>Carers and Social Inclusion by Trish Hill, Cathy Thomson, Margaret Raven, Melissa Wong, Bettina Cass, Sue Yeandle, Lisa Buckner, UNSW Social Policy and Research Centre</p> <p>This research sought to address gaps in knowledge of care and social inclusion, including in Indigenous communities, in Australia and England. It also included a component on young adult carers (YAC) aged 18-25.</p>	<p>Stakeholder and age specific carer focus groups: sites identified in consultation with research partners in NSW and SA (metropolitan and non-metropolitan areas).</p> <p>Check-back/feedback from YCs obtained via Skype and email.</p>	<p>Recruitment through member organisations of Carer Support Network, SA.</p>
<p>Chantelle Day developed the Young Adult Carers in University YACU-Student Experience Framework (YACU-SEF) for her PhD thesis. She interviewed student-YACs (N = 13), carer associations (N = 13) and universities (N=13).</p>	<p>Critical ethnography and case studies (Carspecken and Apple's (1992) critical ethnographic case study process of data analysis).</p> <p>Individual semi-structured interviews via phone or face-to-face (including pre-interview questionnaire via email).</p> <p>Standpoint epistemology/insider knowledge and experience (author was a student-carer).</p>	<p>Promotion and dissemination of poster and flyer through carer and community support associations (e.g. Carers Australia) and universities (e.g. on websites and in their head offices).</p>

Appendix II: Case studies

Case study: Caring while working

Danielle* is a young Aboriginal woman from metropolitan Sydney. She is 25 years old, working full time, and helps her grandmother in caring for her grandfather who has dementia and a physical disability.

Generally, Danielle felt managers were “*pretty good*” about her caring role. However, on one occasion they had to place her grandfather in a nursing home, as it was the only way her grandmother could get respite. Danielle had started a job and could not take leave immediately. Usually she would care for her grandfather every day after work, but during the COVID-19 pandemic, visiting hours at the nursing home were restricted to the middle of the day:

“I just asked if I could go, a half an hour lunch break, hour and a half leave, and it was basically, this massive issue and they said no... I felt like I was being attacked and I had to justify why I was seeing my grandfather. And that really got to me... I felt like I had to justify my relationship to my grandfather... I already provided enough information.”

After the situation was addressed and she was able to work flexibly, Danielle felt it came down to “*things being lost in translation.*” Would it have been different if it was her child rather than her grandparent? While co-workers said they were understanding and supportive, Danielle felt their “*actions are just telling me otherwise.*”

Being able to take leave and allocated days off has been key for Danielle to provide care so her grandmother can have time for herself. She recognises the impact of caring full-time on her grandmother, and continues to manage her work so she can help care her grandfather:

“*So it's like I'm looking after my pop, but I'm also mindful of my nan. She does this every single day, I can't imagine. It's extremely hard work, not just physically, but emotionally as well.*”

*Pseudonym used.

Case study: Caring during school years 1

Arya* is 19 years old from metropolitan Sydney. She cares for her older sister with disability alongside her parents, who are the primary carers. Her caring role ranges from emotional support to cooking, cleaning, personal hygiene, and more recently transport.

As a private person, Arya didn't talk to many people about her caring role; her friends and teachers thought her need to be extremely organised was just part of her personality. During high school, sometimes she would be tired from taking care of her sister, or struggled with homework. Most teachers just thought she wasn't able to sleep well, but one teacher, "*somehow figured out there was something different*" and approached Arya. She could see this teacher "really cared", which allowed Arya to open up about caring for her sister:

I had that particular teacher for ... five years, in my six years of high school, and it was more like, she would just check up on me. After class, she would be like, just hang out for five minutes ... [and check] how's everything going. And if I was struggling, she'll help me work through it.

...Also, when I revealed it to the rest of the teachers, she kind of took charge and helped me figure out exactly what I could get from each of those teachers without having to expose any more of myself... which was nice, because then I didn't have to continually repeat my story to everyone.

Arya's teacher helped provide leeway around homework and assignments when she needed support, respected her privacy, and did not judge Arya because she was a young carer. This trusting relationship made a positive impact throughout Arya's time at school:

"...I think she was probably the first and only instance where I opened up to kind of someone who wasn't a friend necessarily, someone who was a figure, an authority figure... I graduated nearly two years ago, and I still keep in contact with her because she now knows who I am."

*Pseudonym used.

Case study: Young carer networks

Jack* is a 19 year old young carer from regional NSW. He has been caring for his mother who has lived with mental health issues, depression, anxiety, and panic attacks since about the age of five. He completes household duties such as cooking and cleaning, along with arranging and attending medical appointments. Jack has strong connections with carer support, having been involved with the Carers NSW Young Carers program for many years, as well as local services.

In high school, Jack started a club for young carers with the help of the Head Teacher Welfare and his Year Advisor. He felt it was important “having good friends that you can talk to”, including those with shared experiences of caring. The group met at lunchtime and one session each week for about a year:

“So we started off by bringing in some snacks, by playing some board games, by sharing with people who wanted to share... I still remember to this day some young carers in the room saying, “There’s some people in this room, in my year, that I didn’t even realise were a young carer.”

The club catered for students from low socio-economic backgrounds, provided free or low-cost activities, and was an informal space that focused on students’ interests. It also helped that Jack was well-known in the school community, and took the lead and initiative to connect with other students.

Organising a formal group had its challenges, “*because there’s all the paperwork ... that needs to be sorted out*”, but some supportive teachers helped him set up the group. They were also available for referrals and duty of care:

“...I’m lucky I had the support of the Head Teacher Welfare and my Year Advisor. And I was able to debrief with them afterwards, if anything did become a bit too much now. I did see the counsellor maybe once or twice there at the school just to talk about what was going on, as well. But after about three sessions, I learned to not take it in as much.

“...They [staff] were there for maybe the first two or three sessions to supervise, and then after that, they were just in a room nearby. And if somebody wanted to talk, and they didn’t feel comfortable talking to me, they could go to ... the Head Teacher of Welfare, or the Year Advisor.”

Jack felt the club made a “*huge difference*” because it provided a space for “*that common understanding*” where other students may not be able to understand the carer experience:

“...a few of them even broke up in tears when they were telling their stories, ‘cause they said, “This is really the first time I’ve been able to connect with other people that are in similar situations to what I am.” So really, made a big impact. And I said, “This is my respite. My self-care, just going away for an hour or two, just forgetting about what’s going on.””

Approximately 30 young carers were involved with the club at the one school. Connecting with other young carers increased Jack’s understanding of his own mental health, and social and emotional well-being.

*Pseudonym used.

Case study: Caring during school years 2

Melina* is 24 years old from metropolitan Sydney. She cares for both parents, including her dad with a mental health diagnosis. During high school Melina felt the need to hide her parents' condition: *"I was always sort of ashamed and embarrassed and always felt like maybe I'd be discredited because of it..."*

Melina was responsible for getting herself ready for school and often found it hard to make it on time. She attended a strict all-girls' school and her teachers were unaware of challenges faced by carers, so would often get her in trouble:

"...My uniform and things like that for school wouldn't be the best or I would wear a different uniform, and the teachers would get me in trouble, and it was the least of my worries... they were very strict about punctuality... I felt like I was always getting in trouble at school and then I had to go home and deal with more crap."

They referred Melina to the counsellor when she was 15 or 16 years old as they, *"saw that I was not really concentrating in class and I was a bit naughty here and there."* It was not until this point that more of her teachers were made aware of her situation. However, this resulted in a complete shift in the way that teachers treated her, which unfortunately did not feel supportive:

"...I remember being really upset because it was like they completely shifted because they now maybe pitied me... They always just thought I didn't want to follow the rules or come to school early and things like that. And they thought it was a deliberate choice, as opposed to when they knew what was happening and stuff, then they thought, "Oh okay. It's not really in her control." So they changed. But I wish that they had had that thinking prior towards any child."

When reflecting on how teachers could better support young people with caring responsibilities, Melina felt it was important to not assume that a student is purposefully trying to do the wrong thing: *"...I think they should try and work out what's underneath that behaviour, rather than just label that child or give them punishment."*

*Pseudonym used.

Case study: Accessing services

Nadi* is a young Indian woman from metropolitan Sydney and is studying at university. She is 20 years old and has been providing care for her mother over the last decade. From a young age since they migrated to Australia, Nadi would help with English translation and filling out paperwork. As she got older, Nadi provided more mental health support including organising and attending meetings, and errands such as grocery shopping.

One night her mother experienced a severe mental health episode and no one else was home at the time. Nadi didn't know what to do, decided to call Kids Helpline but was unable to get through. She ended up calling the police who came and assessed the situation, put her mother under an involuntary treatment order, and took them to hospital.

The hospital staff did not recognise Nadi as a young carer, yet she had to communicate and translate for her mother as no translator was provided. At one point, Nadi was told to leave and wait in the waiting room.

“So, being a young carer in a hospital as well, I didn't feel like I had any support from staff or, yeah, I was very much looked down upon.”

It was a very distressing experience and did not lead to further support for her family. This impacted Nadi's own health and wellbeing, so she saw the university counselling service but it did not meet her needs:

“I did see ... counselling and psychological support, at the university; and they ended up shaping it around how that might affect my studies, which I didn't understand. I was like, “I didn't come to you to talk about how it's affecting my studies, I came to you for support.” ... I've just been told that is a short term service and they can't really do anything.”

Soon after the incident took place, Nadi was studying a mental health unit for her degree. One assignment was specifically about involuntary treatment orders and Nadi was asked to present on this topic. Despite not feeling ready, Nadi's, lecturer “didn't respect that” because of the opportunity for her peers to “hear about a lived experience perspective”. The situation was not managed in a trauma informed way, as Nadi was not given the agency to decide whether it was the time to share her experience.

Despite these adverse experiences and minimal access to supportive services, her studies and casual work in the disability space have in many ways complemented Nadi's caring role:

“I find that work quite rewarding, and I am learning a lot about what my rights are... A lot of that work requires facilitating programs and activities. And whatever I implement there, I end up just implementing at home as well.”

In terms of what could be improved to support young carers, Nadi believes it is important to have culturally and linguistically diverse people represented in services, to have the experiences of young carers validated, and that services follow up with meaningful support.

*Pseudonym used.

Appendix III: Project Advisory Group membership

The Project Advisory Group for the Young Carer Research Project consisted of the following members:

- Paula Gleeson, Senior Social Researcher, Centre for Carers Research, UTS
- Dr Myra Hamilton, Associate Professor, Principal Research Fellow, The University of Sydney Business School
- Dr Karen Hutchinson, Postdoctoral Research Fellow, Australian Institute of Health Innovation, Macquarie University
- Dr Abner Poon, Senior Lecturer, School of Social Sciences, Faculty of Arts and Social Sciences, UNSW
- Cathy Thomson, Research Fellow, Social Policy Research Centre, Faculty of Arts and Social Sciences, UNSW
- Alex Berger, former young carer and Young Carer Leader, Carers NSW
- Amanda Sharma, former young carer and Carer Representative, Carers NSW
- Sarah Judd-Lam, Manager Policy and Research, Carers NSW
- Natalie Steinhardt, Young Carer Project Officer, Carers NSW

Appendix IV: Selected research materials

Participant Information and Consent Form

Department of Sociology
Faculty of Arts
MACQUARIE UNIVERSITY NSW 2109
Email: lukas.hofstaetter@mq.edu.au



Chief Investigator: Dr Lukas Hofstaetter, Department of Sociology, and Carers NSW
Co-Investigator: Sienna Aguilar, Carers NSW

Participant Information and Consent Form

Name of Project: (6233) 2020 National Carer Survey/Young Carers Substudy

You are invited to participate in a study engaging young people with a family member or friend who has a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness or who is frail. The purpose of the study is to explore the experiences and support needs of young people (aged 16 to 25) in NSW in regards to caring, study, work, participating in their community, and accessing services. It aims to identify strategies to improve engagement based on young people's lived experiences, and will help inform the development of resources to support young people's access to relevant programs, services, and other projects.

The study is being conducted by Dr Lukas Hofstaetter (lukas.hofstaetter@mq.edu.au) and Sienna Aguilar (02 9280 4744, sienna@carersnsw.org.au).

If you decide to participate, you will be asked to attend a 2-3 hour focus group (face-to-face or via video conference). If you cannot attend a focus group, you may participate in an 1 hour interview (face-to-face/online/telephone) instead at a time convenient to you. The focus group or interview will be audio-recorded only if all attending participants give permission, and a facilitator will take written notes to make sure we capture your feedback accurately. You will be invited to read the transcript and offer follow up feedback by email if you wish.

There may be some discomfort associated with sharing personal experiences. Participants can choose to share what they wish/what they answer. If you feel the need to talk to someone after the focus group or interview, the following services are available:

Carers NSW
(9am – 5pm Monday to Friday)
02 9280 4744

Lifeline Australia
(24 hours)
13 11 14

In an emergency, call Triple Zero 000

Lifeline Text
(6pm – Midnight, 7 days a week)
0477 13 11 14

Participants can access support to participate (e.g. for transport costs, accommodating time for caring responsibilities etc.) and will receive a \$50 gift voucher for attending either a focus group or interview. You will also receive an optional Certificate of Participation if desired.

Any information or personal details gathered in the course of the study are confidential, except as required by law. No individual will be identified in any publication of the results, except if a participant wishes to be named in the acknowledgments of the final report on a case by case, opt in basis. No individual will be identified in relation to specific data or findings. Only the named investigators will have access to personal data.

The final report with a summary of findings will be made available on the Carers NSW website and upon request by emailing sienna@carersnsw.org.au.

Participation in this study is entirely voluntary: you are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence.

I, *(participant's name)* have read *(or, where appropriate, have had read to me)* and understand the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this research, knowing that I can withdraw from further participation in the research at any time without consequence. I have been given a copy of this form to keep.

Participant's Name: _____
(Block letters)

Participant's Signature: _____ Date: _____

Please have a parent/guardian complete if participant is under 18:

I, *(parent/guardian's name)* as parent/guardian of: *(participant's name)* agree for my child to participate in this research, knowing that he/she can withdraw from the research at any time without consequence.

Parent/Guardian's Name: _____
(Block letters)

Parent/Guardian's Signature: _____ Date: _____

Investigator's Name: _____
(Block letters)

Investigator's Signature: _____ Date: _____

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics & Integrity (telephone (02) 9850 7854; email ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

(INVESTIGATOR'S [OR PARTICIPANT'S] COPY)

Frequently Asked Questions (FAQ) for participants

Who can take part in this research project?

Young people (aged 16 to 25 in NSW) with a family member or friend who has a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness or who is frail.

The flyer says this project is for young people with unpaid caring responsibilities, but I am on the Carer Payment. Can I still take part?

An unpaid carer is someone who cares for a family member, partner or friend, whether or not they receive an income support payment from Centrelink, like Carer Payment. By 'unpaid', we just mean that the care they provide is not part of their paid job, but rather a role they take on to support a family member, partner or friend.

What is the research for?

The purpose of the study is to explore the experiences and support needs of young people (aged 16 to 25) in NSW in regards to caring, study, work, participating in their community, and accessing services.

It aims to identify strategies to improve engagement with young people with caring responsibilities through understanding their experiences. It will help Carers NSW to develop resources to support young carers to access relevant services and programs.

Who is conducting the research?

The study is being conducted by Dr Lukas Hofstaetter (Carers NSW and Macquarie University, lukash@carersnsw.org.au) and Sienna Aguilar (Carers NSW, 02 9280 4744, sienna@carersnsw.org.au).

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee (Project ID 6233).

What do I have to do?

1. Read, sign and return a Participant Information and Consent Form via email to sienna@carersnsw.org.au one day before or on the day of the interview.
2. Take part in a one hour interview (phone/online) at an agreed time that is convenient for you. The interview will be audio-recorded if you give permission, and the interviewer may take written notes to make sure feedback is accurately captured.
3. Provide current email address to receive a digital \$50 Coles gift card.
4. You will also be invited to read the interview transcript and be able to give follow up feedback by email (optional).

How will the data be used? Will I be identifiable?

Data from interviews will be analysed for key themes and findings. This will then be written up in a report for Carers NSW and organisations interested in supporting young carers. The final report with a summary of findings will be made available on the Carers NSW website and upon request by emailing siennaa@carersnsw.org.au.

Any information or personal details gathered in the course of the study are confidential, except as required by law. No individual will be identified in any publication of the results, except if a participant wishes to be named in the acknowledgments of the final report on a case by case, opt in basis. No individual will be identified in relation to specific data or findings. Only the named investigators will have access to personal data.

What are the risks with participating?

There may be some discomfort associated with sharing personal experiences. You can choose to share what you wish and decide which questions you answer. If you feel the need to talk to someone after the interview, the following services are available:

[Young Carers, Carers NSW](#)
(9am – 5pm Monday to Friday)
02 9280 4744

[Lifeline Australia](#)
(24 hours)
13 11 14

[Kids Helpline](#)
(24 hours)
1800 55 1800
<https://kidshelpline.com.au/>

[Lifeline Text](#)
(6pm – Midnight, 7 days a week)
0477 13 11 14
<https://www.lifeline.org.au/>

In an emergency, call
Triple Zero 000

Why take part?

It's important for organisations supporting the community to be informed by young people, including those with unpaid caring responsibilities helping a family member or friend who has a disability, mental illness or health condition.

It's also important during times of change and system reform, to make sure the views of young carers are heard. Taking part in this research will help Carers NSW develop resources to support young carers to access relevant services and programs.

You can access support to take part (e.g. accommodating time for caring responsibilities etc.) and will receive a \$50 gift voucher for completing an interview. You will also receive an optional Certificate of Participation if desired.

Do I have to participate? What if I change my mind before or during the interview?

Participation in this study is entirely voluntary: you are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence.

How can I take part?

Contact Sienna Aguilar, Young Carer Project Officer, Carers NSW on 02 9280 4744 or email siennaa@carersnsw.org.au to organise an interview between 14 April to 7 May 2020.

Interview questions

The following questions and prompts were used as a guide to explore key topics, and were not necessarily asked in order as per the semi-structured interview approach.

Caring context (approx. 10 min)

1. Could you tell me a bit about yourself and who you provide care for (no names required)?
 - Participant's relationship to the person they care for
 - When it started, how long they have been caring for them
 - Types of caring (e.g. from flyer: cooking/cleaning/washing; shopping/paying bills; taking medication; driving/going to appointments etc.)
 - Ease into carer identification as appropriate e.g. when did they realise they were providing care?

Caring experiences and needs (approx. 20 min)

2. What has it been like managing studying or working with your caring role?
 - Prompt for current situation (e.g. year level, part-time, school leaver etc.)
 - Explore strengths and challenges of caring
 - Bonus question for university student carers: how well does the university support your studies as a carer? Are you aware of support available?
3. What has it been like managing caring with your social life or extra-curricular activities?
 - Explore time spent with friends and family, talking to others about caring role etc.
 - Explore participation in community, extra-curricular activities, university life, hobbies etc.
 - Explore carer networks, if there are any other (young) people in their life that may also help care for a family member or friend (potential participant referral)
4. Have you ever felt the need to reach out for help for yourself?
 - Explore if they have sought support (if so, what and how helpful was it; how did they find out about services; if not, why not, are they aware of what is available etc.)
 - Example prompts: informal support from friends/family; respite ("have a break"); counselling; student welfare services; carer support group, mental health etc.
 - Bonus prompt if recruited from youth/community organisation and they currently access services: explore what support they have valued and what has helped them to access support
5. What has been most rewarding in your journey as a young person caring for someone?
 - E.g. what have you learnt about yourself or the person you care for? What experiences do you appreciate? What skills or attributes have you developed through being a young carer?

Engagement and support (approx. 20 min)

6. Carers NSW is interested in how young people access information and where they may go to look for information or support.

[If participant has accessed [x] services as per Q4]: How did you find out [x]?

If you were to look for support for yourself around study/work arrangements/finances/mental health (as relevant to participant), where would you go?

- E.g. at school/university, specific social media channels, places in local community, online, specific services/organisations
 - Explore preference for online versus face-to-face engagement, electronic versus hard copy materials etc.
7. Thinking about your own caring journey and when you needed information or support, what did you find helpful/unhelpful? Is there anything you wish you learnt about earlier about caring?
- Explore specific examples, potential challenges and enablers to accessing information etc.
 - Explore preference for online versus face-to-face engagement, electronic versus hard copy materials, frequency of communication etc.
 - If appropriate, refer to their comments about the term “carer” and what the phrase “young carer” means to them
8. What might help you in your caring journey?
- E.g. In what ways could school/university/workplace; friends/family; service providers; or help you as a young person caring for a family member or friend?
 - What services, support systems, arrangements (e.g. flexible) would you find helpful to better support you (as a young carer)?
 - If specific types of support are mentioned (e.g. counselling, support group with other young carers etc.), explore for preferences around online/phone/face-to-face engagement
9. What advice would you give other young people who might help care for a family member or friend with a disability, mental illness or health condition?

Example prompts: These tips could be around self-care or how to navigate the system. Think about what has worked for you. What advice/tips you would have appreciated when you first became aware that you were a young carer? What would you want to hear now?

Wrap up (approx. 5 min)

10. I'm just going to ask a few questions about your demographic background.
- a. What is your age?
 - b. What is your gender? (Female/Male/self-described/prefer not to disclose)
 - c. What cultural background(s) do you identify with?
 - d. Do you speak a language other than English at home?
 - e. Are you of Aboriginal or Torres Strait Islander origin?
 - f. Do you, yourself, identify as living with a disability or health condition?
 - g. What geographic region are you located in?
11. Are there any other young people you know that may also help care for a family member or friend, and who might be interested in this project?
12. Is there anything else you would like to say before we start to wrap up?

Appendix V: Flyers

Flyer for participants

Your voice matters

Young Carer Research Project

Carers NSW would like to hear from young people with unpaid caring responsibilities

Are you:

- 16 – 25 years old?
- Responsible for helping a family member or friend who has a disability, mental illness or health condition?

Do you help with (any of these tasks):

- Cooking, cleaning, or washing
- Shopping or paying bills
- Looking after siblings
- Translating for a family member who does not speak English
- A shoulder to lean on (listening, being encouraging)
- Monitoring moods and behaviours
- Taking medication
- Bathing, feeding, or toileting
- Lifting/moving
- Dealing with emergencies
- Driving or going to appointments

Why take part?

- Have your say as part of research to help other young people
- Get involved at a time that suits you
- Certificate of Participation (optional)
- \$50 gift voucher

When?

March to early May 2020

One hour interview (phone or online)

Take part or find out more

Contact Sienna Aguilar, Young Carer Project Officer, Carers NSW on 02 9280 4744 or email siennaa@carersnsw.org.au

If you are seeking support you can contact Carers NSW Young Carer team on 02 9280 4744 (9am – 5pm Monday to Friday).

www.youngcarersnsw.org.au
or Google "young carers NSW"

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee.

**Do you know
a young person
who cares
for a family
member?**

Young Carer Research Project

Carers NSW would like to invite young people (aged 16-25) with unpaid caring responsibilities to take part in a phone or online interview as part of a new research project.

This study aims to identify ways to improve engagement with young people through understanding their experiences. It will help us to develop resources to support young carers access relevant services and programs.



What are the benefits for young people?

- Contribute to important research in a safe, confidential and inclusive environment
- Flexible time to suit young person
- Certificate of Participation (optional)
- \$50 gift voucher

When?

March – early May 2020,
one hour interview (phone or online)

Where can I find out more?

Contact Sienna Aguilar, Young Carer Project Officer, Carers NSW on 02 9280 4744 or email siennaa@carersnsw.org.au

Young carers who may be seeking support can contact Carers NSW Young Carer team on 02 9280 4744 (9am – 5pm Monday to Friday)

www.youngcarersnsw.org.au or
Google "young carers NSW"

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee.

Appendix VI: Description of selected Carers NSW programs

19 participants had existing association with Carers NSW prior to this research project. Information about the programs they had engaged with are below:

Carer Representative Program

Carer Representatives play an important role by representing carers and Carers NSW in a variety of settings and sharing their caring experiences with service providers, government, the media and broader community.

Carer Representatives are specially trained carers who are offered opportunities to speak up for carers to help improve the system for all carers and the people they care for. Among other things, Carer Representatives may be requested for media interviews, public forums, focus groups, committee/panel work and policy advice.

Carers NSW Young Carer Program

The Carers NSW Young Carer Program was developed to make a positive difference in the lives of young carers and their families through a range of initiatives aimed at reducing these challenges and increasing opportunities for positive outcomes.

The Young Carer Program supports and connects young carers through:

- an interactive Young Carer website
- access to exclusive online forums
- counselling
- emotional support
- information and referrals
- e-newsletters
- young carer awareness workshops
- young carer opportunities and events, including leadership development activities

Carers NSW Carer Achievement Pathway Program

The Carer Achievement Pathway Program was an innovative project was funded under the Try, Test and Learn fund, an initiative of the Australian Government's Department of Social Services. It aimed to work with young carers to increase their readiness to participate in employment or education and support them in their caring role. Support included:

- tailored one-to-one support over 12 months, depending on participant's needs and engagement, to help address barriers to education/employment
- coordinator and volunteers available to mentor
- digital platform and goal setting, including optional reviews throughout the 12 month period
- referrals to other services

Appendix VII: Facilitators and barriers to engagement

The following table outlines key factors that facilitated or were barriers to engaging young carers across education, employment, and service provision. These can also inform engagement for research and consultation purposes.

Enablers	Barriers
Trustworthy and supportive interactions (e.g. with parent, teacher/counsellor/service provider of care recipient)	Lack of carer awareness (e.g. in school, health service, workplace)
Connecting with other young carers and their stories	Lack of available information at school/educational institution
Carer aware service providers or workplaces	Negative experiences (e.g. with services, stigma)
Resourcefulness of young carers to access (digital) information	Lack of time
Inclusive and jargon-free language	