



Young Carers in Australia Project 2021:

A summary of key findings and recommendations

Research examining:

- *roles of Young Carers*
- *health and wellbeing of Young Carers*
- *educational and work outcomes for Young Carers, and*
- *support for Young Carers*

Young Carers in Australia Project 2021

Hutchings, K., Harris, N., McMillan, S., Radford, K., Slattery, M., Spencer, N., & Wheeler, A. 2021. Young Carers in Australia industry research report, Griffith University: Brisbane, Australia.

Graphic design

Liveworm Studio Gold Coast, Sharon Searle, Skye Smith, Hannah Ison.

Acknowledgements

The project was funded by Arafmi Ltd and Little Dreamers (Griffith University project reference number: 03/07/4790-02).

The authors acknowledge research assistance provided by Elisha Roche and Sarah Birtwistle at Griffith University

The authors also acknowledge advice throughout the project by the Project Advisory Board including: Irene Clelland (CEO, Arafmi Ltd), Alex Tyson (Service Delivery Manager, Arafmi Ltd), Cassie Lieschke (at the time of research - Impact Measurement & Research Analyst, Little Dreamers), Professor Melanie Zimmer-Gembeck (School of Applied Psychology, Griffith University) and Abi Cooper (young carer)

Ethics approval

Griffith University HREC: 2020/786

Contents

02

Executive summary

03

Introduction

05

Literature review

06

Research methods

07

Findings

12

Conclusions

15

Recommendations

16

References



1 Executive summary

The project examined Young Carers (hereafter YCs) in Australia. Specifically, the project explored:

- caring roles of YCs in Australia,
- health and wellbeing, psycho-social disability and risk-taking behaviours of YCs in Australia,
- implications of caring responsibilities for educational and employment outcomes of YCs in Australia, and
- support, barriers to support, and further support needs for YCs in Australia.

The research involved:

- a review of earlier research on YCs,
- interviews with stakeholders involved with YCs,
- a nationwide survey of YCs (aged 9–24), and
- interviews with YCs (aged 18–24).

The research led us to conclude there is need to raise awareness about:

- the prevalence of YCs in our communities,
- the diverse roles YCs undertake,
- the transferability of YCs' skills to workplaces,
- the range of support currently available to YCs, and
- additional support that is required for YCs.

We recommend:

- increasing support services available for YCs and the accessibility of such services,
- financial assistance for YCs with their caring role,
- support to mitigate mental illness and risk-taking behaviours of YCs,
- key stakeholders, including government, the secondary and tertiary education sectors, employer groups, and unions, need to work to facilitate YCs completing their education (including post-school qualifications), and maximising their participation and potential as employees.

2 Introduction

The YCs in Australia Project was undertaken by a team of researchers at Griffith University for Arafmi Ltd and Little Dreamers.

Arafmi Ltd (hereafter Arafmi) is a not-for-profit community-based organisation (founded in Brisbane in 1977 and with operations throughout South-east Queensland) and is a registered provider with the NDIS that provides support for families, carers and people with mental health issues or psycho-social disability (see Arafmi, 2020). Recognising that the experience of mental illness not only affects the individual, but also those people who care about them, Arafmi aims to provide support and education to mental health carers and people living with mental illness.

Little Dreamers (founded in 2009) is Australia's leading YCs organisation that works with, and provides support to, young people across Australia who provide unpaid care for a family member/s with a disability, illness, or addiction. Focused on improving quality of life of YCs, Little Dreamers has a vision that by 2030 every young carer (hereafter YC) will be supported by someone or something. Little Dreamers also aims to develop a peak body for YCs and champions the introduction of a National Carer Act in Australia (Little Dreamers, 2020).



Focus of the research project

The first aspect of the project involved an examination of the extent of caring roles of YCs in Australia. Specific research questions included:

- Research question 1: Who are the YCs in Australia?
- Research question 2: What care is provided by YCs in Australia?

The second aspect of the project examined health and wellbeing, psycho-social disability and risk-taking behaviours of YCs in Australia. Specific research questions included:

- Research question 3: What is the prevalence of psycho-social disability (mental illness/mental health issues) amongst YCs in Australia?
- Research question 4: What is the prevalence of risk-taking behaviours amongst YCs in Australia?
- Research question 5: What coping strategies are used by YCs in Australia?

The third aspect of the project examined the implications of caring responsibilities for YCs' educational and employment outcomes. Specific research questions included:

- Research question 6: What are the implications of caring responsibilities for Australian YCs' educational outcomes?
- Research question 7: What are the implications of caring responsibilities for Australian YCs' employment outcomes?

The fourth aspect of the project involved an examination of the support, barriers to support, and further support needs for YCs in Australia. Specific research questions included:

- Research question 8a: What services are there to support YCs in Australia?
- Research question 8b: Why do YCs in Australia access these services?
- Research questions 8c: How do Australian YCs access these services?
- Research question 9: What barriers are there in accessing support for YCs in Australia?
- Research question 10: What other support services are required for YCs in Australia?



3 Literature review

While the definition of YCs differs slightly across countries, the term generally refers to children and young adults (up to age 24) who provide unpaid care to a family member or friend who has a chronic illness, is frail, aged, or has a disability (physical or mental) (Carers Australia, 2008).

Reports suggest there are 246,000 YCs in Australia, with 50,000 under 15 (Deloitte Access Economics, 2020).



Key issues identified in earlier research include:

- YCs undertake diverse and varied roles including: supporting personal care; mobility assistance; communicating/translating; providing support for caree's healthcare; transport; and housekeeping (Joseph, Sempik, Leu & Becker, 2020; Moore, McArthur & Noble-Carr, 2011).
- Accurate numbers of YCs in Australia specifically are difficult to determine as many who undertake caring responsibilities do not identify/refer to themselves as YCs (Carers Western Australia, 2010).
- A higher proportion of females, people from lower-socio demographic backgrounds, and Aboriginal and Torres Strait Islander people undertake YC roles (ABS, 2018).
- Positive benefits/attitudes about the caring role include: building resilience; increased maturity; a close relationship with the caree; personal growth; and development of life skills (Boyle, 2020; Cassidy, McLaughlin & Giles, 2014; Gough & Gulliford, 2020).
- YCs report negative aspects of the caring role including: limited confidence and self-esteem and minimal hope for the future, and challenges of competing time demands (Collins & Bayless, 2013; Moore, McArthur & Noble-Carr, 2011).
- Emotional burdens can lead YCs to engage in behaviours risky to their own health and wellbeing, including and extending beyond alcohol (Bailey, Regan, Bartlem, Wiggeres, Wye & Bowman, 2019; Cunningham, Shochet, Smith & Wurf, 2016).
- Education of YCs can be severely disrupted as a result of caring and may also have ongoing impacts on their involvement in work throughout their lives (ABS, 2018; Hill, Thomson & Cass, 2011).
- YCs are less likely to be employed and more likely to be receiving an income support payment especially when undertaking full-time care and those who are employed often work part-time hours (Carers New South Wales, 2017; Hill, Thomson & Cass, 2011).
- Caregiving can be a potential health risk and chronic stressor to the YC, placing them at increased risk of developing both physical and mental health conditions (Pinquart & Sörensen, 2006).
- YCs often lack informal and formal support but engagement with formal support services can improve their ability to cope with problems, and alleviate stress (Australian Government, 2017).
- Multiple barriers prevent YCs from accessing support services including: family reluctance to seek assistance for fear of children being removed, feeling guilty asking for help, lack of awareness of suitable support services, poor understanding of how to access services, and accessibility issues such as transport and cost (Cass, Smyth, Blaxland & Hamilton, 2009; Moore & McArthur, 2007).

4 Research methods

Interviews with stakeholders

- Potential interviewees in organisations that support carers were contacted by the research team and referrals from interviewees was used to contact additional interviewees.
- Interviews were conducted with 8 stakeholders between October and December 2020.
- Questions focused on how stakeholders engaged with YCs, how they defined YCs, what YCs' role entailed, impacts of caring for YCs including health and wellbeing, education, and employment, and support for YCs.

Nationwide survey

- The survey was available online between 21st March and 29th May 2021.
- Questions included: respondent demographics, aspects of caring role, impacts of caring on physical and psycho-social wellbeing, impacts of caring on education and work, types of support received, where support was accessed, usefulness of, and barriers to, support, and other support needs.
- Three scales were included that measured wellbeing (World Health Organization-Five Well-Being Index WHO-5; 1998), resilience (Brief Resilience Scale BRS; Smith, Dalen, Wiggins, Tooley, Christopher & Bernard, 2008), and social support (Medical Outcomes Study Social Support Survey 8-item MOS-SS; Ganza et al., 2003).
- The survey included several open-ended questions for respondents to document their experiences.
- The survey was piloted and then input into LimeSurvey to be available online.
- In total 116 organisations were contacted (and the majority agreed) to distribute an email to their databases/publicise through their social media requesting YCs complete the survey.
- Additionally, 19 schools in Queensland were contacted and one school agreed to publicise the survey on school noticeboards/newsletters.
- The survey was also publicised through social media (e.g. Twitter, Facebook), a Griffith University webpage for students to volunteer to participate in research projects, and at food venues across Griffith University campuses in Brisbane, Gold Coast and Logan.
- There were 144 respondents.

YC interviews

- The interview questions explored the caring role in-depth, the impact of caring on the individual's life including education and employment, and the coping strategies or support services utilised.



Photos: Little Dreamers – taken during Big Dreamers retreat

- YCs were able to volunteer for an interview after completing the survey or could contact the research team directly with the details provided in the email request for survey respondents. Potential interviewees were also sought through emails from some organisations who had distributed the survey request, through social media posts (e.g. Twitter), and interviewees were also asked to recommend or pass-on the study information to potentially eligible personal contacts.
- Ten interviews with YCs were conducted between June and August 2021.

5 Findings

Stakeholder interviews – findings

Table 1 shows key findings from the stakeholder interviews and representative quotes.

Table 1: Stakeholder interview findings

Key finding	Representative quote/s
Many young people and children have caring responsibilities but they do not refer to themselves as a YC or a carer. This has implications across their caring experience and for their own wellbeing and life prospects.	“young carers are very under-reported....very many young carers out there who fly under the radar and are unknown because of child safety [not wanting them to be removed by government services], particularly in Indigenous communities where there has been institutionalisation” (Stakeholder interviewee)
Government policy needs to fully encapsulate the whole family’s experience where a member of the family/household requires care. This includes the impact on siblings who may or may not provide direct care.	“.....even if the sibling is providing no or little care.....It’s very different growing up with a sibling with a disability or illness..... they may feel that they’re not loved as much or they’re not as important.....often siblings do grow up with this heightened sense of the needs of other people being more important.....” (Stakeholder interviewee).
There is great diversity in the roles performed (and time commitment involved while providing care including whether a short- or long-term carer) and it is important to recognise differences in care provided by YCs for people with physical illness or disability compared to psycho-social disabilities.	“And that is diverse as every family in a street is diverse....the responsibilities of carers in each family is different depending upon the family.” (Stakeholder interviewee). “.....there’s a real difference between a mental health carer and a carer of someone who has a lifetime physical disability.....mental health.....it can be unpredictable.....unrecognised.....there’s still, unfortunately, quite a lot of stigma around mental illness in Australia....It’s much easier for young people to say my mum has cerebral palsy.....versus my mum is unwell and hears voices” (Stakeholder interviewee).
Positive aspects of the YCs’ role included a sense of pride in helping others and contributing	“.....it’s that self-satisfaction of actually being an important part of the family who can make a positive contribution.....and decrease some of the negative impacts for the person that they’re caring for” (Stakeholder interviewee).
Negative aspects of the YCs’ role and socio-emotional impacts included not having (enough) time to socialise with friends, a feeling of missing out, isolation, low self-worth, and responsibility burden.	“I think because of the caring role it’s barriers engaging properly in school and their friendship networks...It impacts their social wellbeing and friendships and also for some young carers school attendance...not.....participate in social events or sporting events” (Stakeholder interviewee).
YCs may experience a range of physical and psycho-social health issues and engage in risk taking behaviours.	“.....it can.....negatively impact the trajectory of their life.....So, for some young people there is that.....I’m going to be a carer and this is going to be my job.....difficulty in making sure that they maintain their own hopes and dreams” (Stakeholder interviewee). “.....a lot of them [YCs] have reported that they do self-harm.....There was a couple who take parents’ prescriptions because it’s just like they just want to escape and they just can’t see a way out” (Stakeholder interviewee).

Key finding	Representative quote/s
<p>There may be greater challenges for YCs in remote/regional areas and for YCs from culturally and linguistically diverse backgrounds especially in respect to problems accessing support.</p>	<p>“And those that are isolated, either because they come from culturally and linguistically diverse backgrounds or because they’re rural and remote, or because they come from non-traditional family structures, might have a greater degree of marginalisation. It depends upon the support network, obviously” (Stakeholder interviewee).</p>
<p>YCs’ engagement with education and educational outcomes are directly related to caring responsibilities but there is insufficient recognition within educational institutions.</p>	<p>“.....many of them have been at risk of school exclusion, because they have missed too many days.....they’re not able to get their assignments in, their grades are too low....then.....for young people re-entering into education if they’ve had to take time away for their caring role is..... it’s too hard to go back.....teachers and educational staff.....[need to] consider that this young person might actually be going home and doing a whole lot more work in..... managing a whole household or supporting a family member.....” (Stakeholder interviewee).</p>
<p>Further support for education which could be provided includes: flexible scheduling of classes, peer/one-on-one learning, financial support for education, extensions of time for assessment items, extra support/time from teachers, and time/respite away from home to focus on study.</p>	<p>“There’s no structural policy that actually says that we recognise the caring responsibilities of young people in secondary and tertiary education and gives them additional support resources, like we would a student with a disability” (Stakeholder interviewee).</p>
<p>YCs are perceived as having many qualities (transferrable as workplace skills) but caring impacts on YCs’ work in respect to: difficulties in gaining and maintaining regular work, working only part-time, insufficient flexibility in workplaces, and stigma.</p>	<p>“.....I found out a lot of them don’t even have laptops so they can’t even apply for jobs online, which is basically where everything goes now. It’s all online” (Stakeholder interviewee).</p>
<p>The COVID-19 impacted on YCs because schooling or working from home meant no respite from caring.</p>	<p>“.....their school or their part-time job is their respite. So, the impact of working from home means they’re not getting a break from that caring role. They’re trying to manage both their employment or their education alongside assisted daily living without any break” (Stakeholder interviewee).</p>
<p>Policies and practices organisations could implement to support YCs include: management and staff recognition of (diversity of) caring and making allowances, flexible work hours, personal leave without explanation, referral to support services.</p>	<p>“.....we know that the businesses that are good at supporting carers are those that see not just the employee as an employee, but the employee as a member of the community and family, and.....make those accommodations” (Stakeholder interviewee).</p>
<p>Support for carers included Carers Australia (which also has state branches and a YCs Network), Carer Gateway, Wellways, COPMI, and Arafmi but there is limited support for YCs specifically except for organisations like Little Dreamers and Kookaburra Kids. There are barriers for YCs in accessing support.</p>	<p>“A young carer doesn’t necessarily Google young carers and then find agencies. It’s often connecting in through community mental health or.....through a GP.....or primary youth health nurse.....we need those key people as a community.....to understand young carers.....identify them and knowing agencies to connect” (Stakeholder interviewee).</p> <p>“.....being identified as a young carer.....teachers often don’t have time....they’ve got their own time pressures.....” (Stakeholder interviewee).</p>

Survey of YCs (aged 9-24) - findings

Key findings from the survey were:

- Most respondents provided care to a parent/stepparent or grandparent although some also cared for siblings and other family/community members.
- Caring involved diverse responsibilities, for a range of reasons and for a wide range of physical and psycho-social disabilities, and other situations necessitating care.
- More than a third of respondents provided care for someone who had a physical health condition and a quarter provided care to someone living with a mental health condition.
- Most respondents did not have enough time for themselves and felt alone in their caring role.
- About a third of respondents used alcohol and a small but not insignificant percentage used other substances or harmed themselves because of their caring responsibilities.
- Almost a quarter of respondents were often or very often late for class.
- A small percentage of respondents often or very often dropped out of studies because of money problems and around a tenth dropped out because of other unspecified reasons.
- Almost two thirds of respondents were sometimes late for work, with over half taking days off work because of their caring commitments, and almost half felt they were overlooked for promotion opportunities. Over three quarters of respondents felt uncomfortable talking about their caring role with their co-workers and employers, though just over half felt supported by their employer.
- For respondents who did not receive help with caring key challenges included not knowing what support was available, worrying about money to pay for services, and limited services in their area.
- Support opportunities were mostly identified via family, friends, support associations and health professionals.
- Almost a third of respondents found it difficult to find support programs but of those who received support, the most reported help from the support was improving their confidence and clarity about providing care.
- Most respondents wanted extra support especially more assistance with household duties, keeping them safe, looking after siblings, transport, personal care and financial.
- Most respondents believed financial support for their education and personal needs would be very/extremely helpful. Almost two thirds believed advice on their future education and career would be helpful. Around two thirds said they would like help with caring to have more time for themselves.
- In the qualitative feedback respondents identified challenges with being a carer and highlighted positive aspects of being a carer. They also identified support that would help including: mental health support, support groups/connections, preparation for the future, carer education, time for self, activities and resources, and help with caring/respite.

*“Sometimes I feel like I am constantly two steps behind everyone else my age. I wish that I were able to have the same opportunities as everyone else my age”
(YC survey respondent).*

*“Amongst all the struggles and challenges nothing else brings me more joy than to be able to be a carer for my younger brother”
(YC survey respondent).*

YCs (aged 18-24) interviews – findings

Table 2 shows key findings from the YC interviews and representative quotes

Table 2: YC interview findings

Key finding	Representative quote/s
Whilst YCs collectively undertook a broad range of tasks to assist their respective caree/s, most of which were related to Activities of Daily Living, each caring circumstance was unique.	<i>"Yes, for my two brothers I mainly do emotional support and things like making sure that they do their homework. When I was living with my mum in the family home, it would be cooking meals, showering, that sort of stuff but now not so much. With my mum and my grandma, I just make sure that they take their medication.....that they take care of themselves" (YC interviewee).</i>
Caring was akin to parenting in that it was never far from a YC's mind. The role was constant, yet could change, with some YCs having less responsibility with time whilst others undertook more caring tasks.	<i>"The thing is I've always thought that I had to keep up with the caring role as long as the person I'm caring for is still alive, or for some reason somebody else decides to take on the role full time. Otherwise, I always felt like I - there was no other choice but for me to care for them. I never really thought about what I would do if all of a sudden I wasn't a carer anymore. It actually never occurred to me" (YC interviewee).</i>
Positive outcomes were not solely directed towards the caree; all YCs described areas of development in life skills as well as personal growth, particularly in emotional intelligence and an increased sense of protection and advocacy for others.	<i>"And that's something that a lot of people noticed about me when I was growing up. Like, I was just doing a bit better in terms of emotional intelligence compared to my peers. And also learning how to be selfless as well. Like, thinking more about the other person than just about myself. And also as a health student as well and a future health practitioner, being able to care for someone taught me so many things that I could actually learn as a health practitioner as well" (YC interviewee).</i> <i>"For me even if I'm nervous to speak if I'm helping at least one person even if it be a young carer to know that they're not alone or just educating someone then I'm happy to do it" (YC interviewee).</i>
There were key challenges experienced by YCs, particularly isolation which could be viewed as more problematic during a time (teenager, youth) commonly associated with developing a sense of self and building social connections.	<i>"...I mean, in stories that we tell of our childhood, like, oh, I didn't do this, I didn't do that, or like family trips away. We didn't do many of those, or they were very different to other people's but like, actually connecting with kids my own age at the time was very, sometimes hard 'cause I couldn't, I didn't have the same experiences to bounce off. And sometimes I just felt a bit behind" (YC interviewee).</i>
Some obstacles were noted with respect to education, employability (gaining and maintaining, especially casual positions), and personal wellbeing, with specific support requested to address these areas and greater flexibility, e.g. extensions/special consideration for assessment items for those in school or tertiary studies, flexibility in tertiary studies entrance exams, more carers' leave and flexible hours and work from home options for those in work.	<i>"...A lot of teachers will be like, you didn't hand in your homework, why didn't you hand it in? And I'll explain it and then they'll be like, that's not an excuse everyone's got a family. And I was like, no you don't get it but okay" (YC interviewee).</i> <i>"I did go to counselling and welfare about that. But I felt like they, like I said, [university name] they didn't really offer proper support to carers...So at the time, what they were offering, I felt like it didn't really help me in terms of ensuring that I could continue with my studies, other than saying like to me, what I could do is have a leave of absence, like apply for that so that I can still be a student at the university. I still have my place, but I can take a break" (YC interviewee).</i> <i>"...when I was studying for the final year 12 exams, I couldn't devote as much time, compared to everyone else. My friends would be studying for 12 hours a day. And then I could only be studying for six hours a day because I couldn't devote as much time to my studies as they could. I felt that I was a bit disadvantaged, in that way. Also, around the fact that I had to skip multiple school days to attend doctors' appointments with my sister. So, I'm missing out on that education" (YC interviewee).</i>

Key finding	Representative quote/s
Further work is needed to increase overall awareness of YCs in the community, including peers, teachers, and employers.	<i>"My first ever job.....I had to call in or had to go home sometimes from work a fair bit, they kind of were just like, he understood, but he could only give me those days kind of thing, in those times. So, he ended up having to let me go because I wasn't really available enough" (YC interviewee).</i>
Emphasis should be placed on increased understanding of the complexity of YCs' role.	<i>"...I feel like it should be more normalised, I guess, that some people have these roles, and they can be flexible. And I think things like working from home, I think that's really good. Everyone is a lot more flexible about working from home now. And not necessarily doing nine to five at home either..." (YC interviewee).</i>
Important insights were offered by participants for other YCs: to look after their own wellbeing, seek additional help from others with a lived experience and/or from support organisations, and recognition that they are a valued member of the community.	<p><i>"....your caring role, is part of your life, but it doesn't have to consume your whole identity and your whole... You're a whole other person outside of your caring role as well. You have your own personality, you have your own goals, your likes and dislikes. And don't ever let people tell you that you aren't like that. You're just an empty shell, or that you're alone, or that you're not normal" (YC interviewee).</i></p> <p><i>"I think just remembering that in order to take care of the person you're taking care of, you have to take good care of yourself first... just if things get too much, taking some time off for yourself ... have a respite carer come in to look after your family member...just keep in mind that you have to have that time to yourself as well... which we often forget" (YC interviewee).</i></p>

6 Conclusions

With respect to *caring roles of YCs in Australia*, the research found:

- *Many YCs do not identify* as a carer as they and others assume this is a “normal” role.
- *YCs are over-represented* amongst females, Aboriginal and Torres Straits Islander peoples, and people from CALD backgrounds.
- *YCs have diverse care experiences*

In relation to *health and wellbeing, psycho-social disability and risk-taking behaviours of YCs in Australia* the research concluded:

- *There are significant positive benefits arising from caring* including increased resilience and maturity; fostering a closer relationship with the caree; and development of life skills.
- *YCs also experience negative aspects of caring* which may impact their current and future wellbeing. The challenges of competing demands on their time, burden of responsibility and feelings of isolation may result in a reduction in confidence, self-esteem and hope for their future.
- *Mental illness is a significant risk for YCs* with many reporting they did not have enough time for themselves and feel alone in their role. Sleep deprivation is common amongst YCs and a small proportion of YCs used substances (e.g. alcohol) or harmed themselves because of caring.

Implications of caring for educational and employment outcomes of YCs in Australia are:

- *YCs’ education can be severely disrupted* as a result of the caring role and impact future work.
- *YCs have many skills transferable to workplaces* including maturity, resilience, dedication, good organisational and time management skills, budgeting skills, problem solving skills, and empathy.
- *Employment opportunities whilst teenagers may be limited* by the caring role. They may miss shifts, leave early, are considered unreliable etc and miss connections with other young people.
- *Adult employment participation is limited* with some YCs on income support providing full-time care or only able to work part-time and being overlooked for promotion opportunities.
- *YCs need skills in communicating about their caring role and negotiating support* with most uncomfortable talking about their caring role with their co-workers and employers.

In regard to *support needs, and barriers to support, for YCs in Australia*, the research found:

- *There is limited support for YCs specifically and even fewer targeted for different age groups.*
- *Many YCs do not seek support* and often *lack informal and formal support* because of: lack of time to search for, awareness of, and

knowledge of accessing support services, reluctance to seek help, feeling guilty asking for help, lack of transport and finances, and not of age to access some support.

- *Support services were most commonly identified* through family/friends and some did their own research. Only a small number received information from GP/nurse or school guidance officers.
- Though support made them feel more confident and clearer about providing care, some *YCs don’t understand how support services can help* improve their own and the caree’s wellbeing.
- *Supports requested by YCs include:* advice about recognising their own needs and developing personal boundaries, mental health support, assistance with household duties, caring for siblings and keeping carees safe, greater acknowledgement of difficulties YCs face, one-on-one support, more provision of training and access to employment, and peer support.
- *YCs in remote/regional areas and from CALD backgrounds need more targeted support.*





7 Recommendations

Hence, we recommend that YC (and general carer) support organisations consider their current support services, and work with other organisations and key stakeholders to:

1. Increase support programs provided to YCs by:

- a. Co-designing support and events with YCs on specific topics/ activities/retreats they would like to have included and have different timing, duration and location of events/workshops.
- b. Offering a mix of both online and face to face support services.
- c. Connecting with YCs through social media that they utilise.
- d. Being clear that services are available whether YCs are primary or secondary carers or providing occasional care for a sibling.
- e. Increasing awareness of YC needs and available support services to (and through) schools, universities, employer groups, and unions, the health sector and family and children services agencies.
- f. Include information and support for YCs by organisations who provide respite services.

Support programs should include communication techniques for health professionals, guidance counsellors, teachers, or similar professions on how to raise the caring role with young people so that they can articulate what support they need.

2. Increase awareness of YC issues to reduce stigma of identification and reluctance to seek and accept support.

- a. Stakeholders include welfare support agencies, the NDIA, education departments at state and federal levels, the university sector, employer groups, and unions.
- b. Key messages include: the workplace transferrable skills of YCs; additional support required by YCs; and the need for alternative sources of support for carers (care at home, respite, mental health care etc). Early intervention is key to protect the YC from potential negative impacts of caring and reduce the risk of a YC embarking on risk-taking behaviours.

3. Policy changes required to support YCs, acknowledging the important role YCs undertake, and benefits to Australia if YCs are active labour force participants.

- a. Carer payments for YCs aged 14 and above given the demands on their time preventing them being able to undertake employment opportunities.
- b. YCs viewed as a priority group for the development of interventions to ensure education attainment to maximise employment opportunities.

- c. Special considerations, career advice and additional funded support for school, vocational and university aged YCs to facilitate school completion and gaining tertiary or trade qualifications. e.g. financial support for education, extensions of time for assessment items, extra support/time from teachers/tutors, respite away from home to focus on study.
- d. Health and wellbeing programs for YCs to build their resilience and self-esteem.
- e. Employer groups and unions should encourage their members to support YCs through management and staff recognition of the caring role and allowances such as: flexible work hours; personal leave taken without providing an explanation; referral to support services; or advocacy services.

8 References

- Arafmi. (2020). *Arafmi*, Retrieved 6th March 2020 from <https://www.arafmi.com.au/>
- Australian Bureau of Statistics. (2018). *Young carers*. Retrieved 1st October 2020 from <https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2071.0~2016~Main%20Features~Young%20Carers~143>
- Bailey, J.M., Regan, T.W., Bartlem, K.M., Wiggers, J.H., Wye, P.M., & Bowman, J.A. (2019). A survey of the prevalence of modifiable health risk behaviours among carers of people with a mental illness. *BMC Public Health*, 19 (1240). <https://doi.org/10.1186/s12889-019-7577-4>
- Boyle, G. (2020). The moral resilience of young people who care. *Ethics and Social Welfare*, 14(3): 266–281. DOI: 10.1080/17496535.2020.1771606
- Carers Australia. (2008). *Background paper: a literature review, young carers and education*. Deakin, Carers Australia.
- Carers New South Wales Australia. (2017). *Young carers: Barriers to accessing employment*. Retrieved 24th September 2020 from https://www.carersnsw.org.au/Assets/Files/Young%20Carers_Barriers%20to%20Accessing%20Employment.pdf
- Carers Western Australia. (2010). *About carers*. Retrieved 21st September 21 2020 from <https://www.carerswa.asn.au/about-carers-wa/who-are-carers-wa/>
- Cass, B., Smyth, C., Hill, T., Blaxland, M., & Hamilton, M. (2009). *Young carers in Australia: understanding the advantages and disadvantages of their care giving* (No 38). Retrieved 1st October 2020 from https://www.arts.unsw.edu.au/sites/default/files/documents/26_Social_Policy_Research_Paper_38.pdf
- Cassidy, T., Giles, M., & McLaughlin, M. (2014). Benefit finding and resilience in child caregivers. *British Journal of Health Psychology*, 19(3): 606–618. <https://doi.org/10.1111/bjhp.12059>
- Collins, J. & Bayless, S. (2013). How caring for a parent affects the psychosocial development of the young. *Nursing Children and Young People*, 25(10): 18–21. <http://doi: 10.7748/ncyp2013.12.25.10.16.e351>.
- Cunningham, L.C., Shochet, I.M., Smith, C.L., & Wurf. (2016). A qualitative evaluation of an innovative resilience-building camp for young carers. *Child & Family Social Work*, 22(2): 700–710. <https://doi.org/10.1111/cfs.12286>
- Deloitte Access Economics (2020). *The value of informal care in 2020*. Carers Australia. Retrieved 10th August 2021 from https://www.carersaustralia.com.au/wp-content/uploads/2020/07/FINAL-Value-of-Informal-Care-22-May-2020_No-CIC.pdf
- Ganza, P., Guadagnoli, E., Landrum, M., Lash, T., Rakowski, W., & Silliman, R. (2003). Breast cancer in older women: Quality of life and psychosocial adjustment in the 15 months after diagnosis. *Journal of Clinical Oncology*, 21, 4027–4033.
- Gough, G., & Gulliford, A. (2020). Resilience amongst young carers: investigating protective factors and benefit findings as perceived by young carers. *Educational Psychology in Practice*, 36(2): 149–169. <https://doi.org/10.1080/02667363.2019.1710469>
- Hill, T., Thomson, C., & Cass, B. (2011). Young carers: location, education and employment disadvantage. *Australian Journal of Labour Economics*, 14(2): 173–198.
- Joseph, S., Sempik, J., Leu, A., & Becker, S. (2020). Young carers research, practice and policy: An overview and critical perspective on possible future direction. *Adolescent Research Review*, 5: 77–89. <http://doi.org/10.1007/s40894-019-00119-9>.
- Little Dreamers. (2020). *About Us*, Retrieved 17th June 2020 from <https://www.littledreamers.org.au/about-us/>
- Moore, T., McArthur, M., & Noble-Carr, D. (2011). Different but the same? Exploring the experiences of young people caring for a parent with alcohol or other drug issue. *Journal of Youth Studies*, 14(2): 161–177. <https://doi.org/10.1080/13676261.2010.522561>
- Pinquart, M., & Sörensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *The Journals of Gerontology. Series B. Psychological Sciences and Social Sciences*, 61(1): 33–45. <http://doi: 10.1093/geronb/61.1.p33>.
- Smith, B., Dalen, J., Wiggins, K., Tooley, E., Christopher, P., & Bernard, J. (2008). The Brief Resilience Scale: Assessing the ability to bounce back. *International Journal of Behavioral Medicine*, 15: 194–200. <https://doi.org/10.1080/10705500802222972>
- World Health Organisation (WHO). (1998). *Use of well-being measures in primary health care: The Depcare project health for all*. Stockholm, WHO Regional Office for Europe.



Contact Us

Griffith University

Nathan campus

170 Kessels Road

Nathan Queensland 4111

E-mail: k.hutchings@griffith.edu.au