

Young people first, carers second

Experiences, perspectives and solution ideas led by the lived experience of young people who provide care in South Australia



Acknowledgements

Thank you to all 52 young people who provide care for creating the essence of our research project.

From the methodology and principles underpinning this research; to designing research questions, conversation guides and activities; to turning up on the day of every research activity, UCWB cannot thank you enough.

The project would not have been possible if you didn't volunteer your time outside of school and during school holidays. If you didn't bring your laughs, tears, vulnerabilities, and complexities to our research activities. And if you didn't open your heart, thoughts, experiences and stories to our research team.

UCWB thanks you wholeheartedly and hope that as an organisation, we amplified your voice and did your story justice.

Thank you to Carers SA, the young carers workforce and The Commissioner for Children and Young People for bringing their insights and sector knowledge into this work, for creating partnerships and collaborative opportunities that centred around young people's voices, and for volunteering time to be involved in our research activities.

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Key terms & definitions

Young People Who Provide Care

Systematically defined as 'young carers', young people who provide care are children and young people under 25 who provide care, assistance and/or support to a family member with a:

- Physical and/or mental health condition
- Drug and/or alcohol problems and/or
- Old age and fragility [1].

Based on 2018 data, 235,000 young Australians provide care for someone, with an estimated number of 22,600 young South Australians providing care for someone [2]. Numbers are expected to be higher as youth caring is underreported due to young people not:

- Identifying as carers
- Presenting to service providers and/or
- Being allowed to 'admit' to caring responses in cases of intervention [3].

Young people's caring responsibilities vary depending on their care recipient's condition [3]. Tasks typically undertaken by young people include:

- Practical tasks, such as cooking, housework, and shopping
- Physical and personal care, such as dressing, washing and self-grooming
- Looking after siblings and/or other family members
- Providing emotional support and companionship
- Managing family budgets and collecting medical prescriptions
- Administering medication or physiotherapy practices
- Organising or providing transport
- Attending medical and other health-related appointments [3].

What is less mentioned in literature are young people's added responsibilities of making care decisions, coordinating care, and navigating complex services and systems to support their care recipient, their family, and themselves.

[1] Little Dreamers (2019). Number of Young Carers in Australia Far Exceeds Initial Predictions. <https://www.littledreamers.org.au/number-of-young-carers-in-australia-far-exceeds-initial-predictions/>

[2] Australian Bureau of Statistics (2016). Census of Population and Housing: Reflecting Australia – Stories from the Census. <https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2011.0~2016-Main%20Features-Young%20Carers-143>

[3] Carers SA (2016). Young Carers – What's Next? Available online at: <https://www.carerssa.com.au/wp-content/uploads/2017/08/Young-Carers-Sector-Forum-Paper-Research-Oct-2016.pdf>

Young people also manage crises on behalf of their family, relating to physical and mental health and wellbeing, in addition to family health and wellbeing, death, finances and debt, housing situations, living and running costs and child protection intervention.

Young Adults Who Provide Care

Same as young people who provide care described above but defined as young people aged between 18 to 26.

National Carers Reform

A commitment by the Australian Government to reform carer services funded by Department of Social Services (DSS). This led to the launch of Carer Gateway – a national contact centre and access point for carer-specific information – and current services in 2021.

Carer Services

Services aimed at ensuring outcomes to carers, delivered by lead and regional delivery partners across Australia. Services include brokerage, bursaries and carer directed support, in-person counselling, peer support, and facilitated coaching.

Youth Services

Services aimed at ensuring better whole-of-life outcomes for children and young people, delivered by youth organisations and staff trained and skilled at providing youth specific responses.



Executive Summary

UnitingCare Wesley Bowden views young people who provide care as experts of their lived experiences. Hence, we engaged in a two-year long research journey and worked closely with and alongside these young people to learn from their lived experiences, to amplify their voices, and to translate their wisdom into actions for sector change. These insights and solution ideas shaped our Young people first, carers second Research Report.

As Chief Executive, it gives me great pleasure to share this piece of work with you.

Put simply,

Young people who provide care want to be recognised, treated, and supported as young people first, carers second.

In this report, young people disclosed their lived experiences, the realities of caring, and unheard narratives that not only shape this statement but are not typically heard in traditional research and service delivery.

Young people explained how services, systems, and the sector shifted for them as a result of the National Carers Reform. They identified strengths and shortcomings of viewing young people from a carer lens, in addition to service gaps that exist across the lifespan.

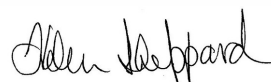
While it is challenging to 'reform a reform', young people are calling for a rethinking of how they are recognised, treated, and supported by their family, people around them, service providers and policy makers – opting to be considered as **young people first, carers second** in all aspects of their life and proposing a model of care that is in alignment with this statement.

With the support of UCWB's Lived Experience Researcher, young people identified small, individual shifts in attitudes, behaviours and perspectives that will make this a reality and lead to wider, collective change across service delivery, policy and advocacy. This all starts by recognising and engaging in the following actions:

- Young people who provide care must not be siloed into system: carer or youth systems. Collaboration and collective efforts are required to enable better outcomes, opportunities for change, and futures for young people who provide care.
- Every young person registered with Carer Gateway must receive a youth-specific response and/or is connecting with a youth service, in addition to receiving carer support.
- Every young person who provides care and who presents to a youth service is responded to as a young person in need, in addition to being connected with Carer Gateway.

UCWB is committed to adapting, evolving and changing the way we do things to do right by young people who provide care. As Chief Executive, I encourage you to do the same in your practice as an individual, as a service and as an organisation and to recognise, treat, and support young people who provide care, as young people first, carers second.

Signed,



Helen Sheppard
Chief Executive, UnitingCare Wesley Bowden



Introduction

As part of the 2015–2016 Federal Budget, the Australian Government announced the National Carers Reform – a commitment to reform federally funded, Department of Social Services (DSS) carer services through an Integrated Plan for Carer Support Services (ICSS).

At the time of this 2018 announcement, more than 100 organisations received state and federal funding to deliver carer services nationwide. 38 were federally funded to operate 54 Commonwealth Respite and Carelink Centres across 52 service areas.

In 2019, 11 organisations (referred to as regional delivery partners or RDPs) were federally funded to deliver the plan and its associated carer services across 31 service areas in Australia.

The plan's overarching objective was to:

Improve carer wellbeing, increase their capacity and support their participation, socially and economically [4].

The plan reflected the Australian Government's priorities for carers and outlined key actions to recognise, support, and maintain the role of unpaid carers in Australia. It was actioned based on the following timeline:

1. In December 2015, DSS announced the Carer Gateway platform – a national contact centre and access point for carer-specific information.
2. Between 2016 to 2017, DSS worked with the sector and carers to design a service model for the ICSS plan that would replace existing carer services at the time.
3. In 2018, service organisations were notified about emerging and imminent changes to the sector and engaged in a nationwide bid to be RDPs. The tender bid closed in February 2019.
4. On 1 July 2019, the online Carer Gateway was launched. Tender outcomes were announced in August 2019. Successful applicants went onto lead RDPs in their service areas, established regional and local presences, and started actioning on services in April 2020.
5. Pre-Reform carer services were extended to May 2020, allowing leeway for transitional efforts to be conducted between previously funded organisations and new RDPs.

[4] Department of Social Services (2018). Integrated Carer Support Service: Regional Delivery Partners: A draft regional delivery model, Australian Government, Canberra.

The ICSS model was proposed to deliver services on three levels: national, regional, and local.

At the **national level**, the model envisioned phone and online counselling services to be delivered centrally via Carer Gateway.

At the **regional level**, RDPs were to deliver carer services, including preventative and emergency supports.

At the **local level**, service providers were to be contracted to delivered services coordinated by RDPs. See Table 1 for further service details.

Table 1: Service offerings from ICSS model

In-Person Counselling

A free counselling service for carers who are experiencing challenges with mental health and wellbeing.

In-Person Peer Support

A free service to support carers in developing skills and resiliences needed for their caring role. Services to be provided in-person via phone or online with a coach.

Carer Directed Support

Carers to receive directed support through the following options:

- Provision of one-off practical support
- Provision of Carer Directed Packages that can be used for a range of ongoing practical supports to assist carers with their caring role.



When notified about sector changes in 2018, UnitingCare Wesley Bowden (UCWB) recognised real and emerging risks of the National Carers Reform to young people who provide care. On regional and local levels, the reform meant that young people who provide care were to be transitioned into generic carer services.

Youth-specific responses, respite options, and individualised support were to be absorbed by lead RDPs nationwide (see Table 2). Their service focus centred on broader carer issues, instead of education and other youth concerns in pre-Reform services. Explicit funding allocations and direct service provisions to youth cohorts were an identified component of Carer Gateway. However, uncertainty existed at the time as service provision for young people who provide care was not clearly defined in the ICSS model.

Table 2: Comparison of pre-Reform and post-Reform services

	Pre-Reform Services	Post-Reform Services
Case management	<ul style="list-style-type: none"> • Accessible through service providers offering family support or adolescent mental health services and/or through UCWB's Commonwealth funded Young Carers Program. 	<ul style="list-style-type: none"> • Accessible through service providers offering family support or adolescent mental health services.
Social Support	<ul style="list-style-type: none"> • School holiday program with other young people who provide care. • Other activities delivered through Carer Support's Raw Energy, Northern Carers Network, UCWB and YMCA. 	<ul style="list-style-type: none"> • Support groups not required to be young people specific.
Respite	<ul style="list-style-type: none"> • Accessed through Commonwealth Respite Programs and Carer Link 	<ul style="list-style-type: none"> • Merged into NDIS, unavailable to many young people.
Financial options	<ul style="list-style-type: none"> • Brokerage for activities to support engagement with school and life (e.g. tutoring, uniforms, transport, driving lessons). • Once off funding (\$3000) to assist with cost of education. • Young Carers Bursary available for young people. 	<ul style="list-style-type: none"> • Financial packages depending on young people's circumstances. • Young Carers Bursary available for young people.
Information	<ul style="list-style-type: none"> • Young people who provide care are assigned to a case manager who provide information and referrals. 	<ul style="list-style-type: none"> • Young people to access generic carer information via Carer Gateway. • Young people to call 1800 number to be linked to SA service providers.

As a commitment to young people who provide care, UCWB turned to lived experience driven research and advocacy to amplify the voices of these young people, translate their wisdom into direct service responses and to advocate on their behalf. In 2019, UCWB received a two-year Discovery Grant from the Fay Fuller Foundation. This led to the employment of a 0.8 FTE Lived Experience Researcher who oversaw the completion of the Young people first, carers second Research Project across 2019 to 2021.

Since then, strong advocacy from Carers SA and Carer Support Network, in addition to UCWB's lived experience driven research, has led to the State's recognition of significant service gaps for young people who provide care in federally-funded Carer Gateway and accompanying service offerings. This had led to state-based changes and commitments to support young people who provide care in 2021. Young people who provide care can now access 12 weeks of intensive support through carer services, as a result of South Australia's Department of Human Services funding.



Background

The Young people first, carers second Research Project followed 52 young South Australians, aged between 9–26, across a two-year journey of change. The project implemented an exploratory qualitative design and incorporated lived experience, narrative perspectives and co-design elements.

Young people who provide care led the conversation, with assistance from UCWB's Lived Experience Researcher and attempted to answer the following questions:

1. What are the experiences of young South Australians who provide care?
2. What are young people's experiences with and perspectives on the National Carers Reform and associated services?
3. How can service providers and policy makers best support young people who provide care?

The Young people first, carers second report was directed towards service providers in South Australia. It provided insights into lived experiences of young people who provide care and realities of caring. It delved deeper into what young people wanted service providers and policy makers to know, to do, and to change for future generations.





Scope

Participant Characteristics

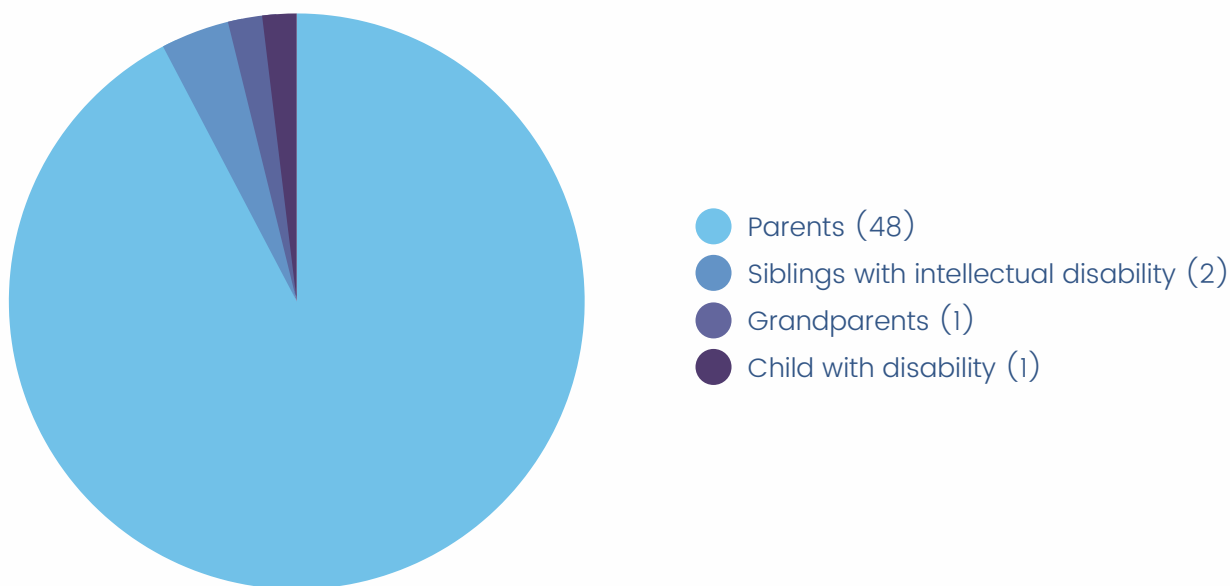
UCWB connected with 52 young people who provide care (37 females, 15 males) aged between 9 to 26. 47 young people provided primary care, while five were siblings who took on some responsibilities within the family unit.

All young people were registered with one of the following services:

- UCWB's federally funded Young Carers Program (now defunded)
- UCWB's Resource Options and Support for Carers (ROSC) program (state funded through SA Health and Office of Chief Psychiatrist)
- Carers SA.

Young people provided care to parents; siblings with intellectual disability; grandparents; and children with intellectual disability. See Graph 1.

Graph 1: Who are young people caring for?



UCWB also had open and honest conversations with the following figures:

- Carers and youth mental health workforce in South Australia
- A national 'young carers' organisation based in Victoria and New South Wales
- Youth advocacy bodies in South Australia
- Independent Commissioners, including the Commissioner for Children and Young People.

Research Journey

In June 2019, a 0.8 FTE Lived Experience Researcher was appointed to oversee and coordinate the research project. UCWB's Lived Experience Researcher was empowered to use their caring experiences to connect with and learn from other young people in similar circumstances.

In July 2019, a Project Design Group was formed and involved five young South Australians who provide care, UCWB's Lived Experience Researcher and UCWB's Young Carers Worker. The design group worked collaboratively to co-design the research project's underlying principles (see Image 1) and methodology that supported UCWB to engage with young people who provide care.

Image 1: Co-Design Principles

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- 1** Focus on the young people, not just the caring role.
 - 2** Understand that young people who care hold significant wisdom when it comes to navigating their life, environment, services and systems.
 - 3** Prioritise building organic connections and authentic team building in earlier stages and throughout research.
 - 4** Give young people space and time to connect and familiarise themselves with peer and staff.
 - 5** Build young people's own concept of their roles and responsibilities within research.
 - 6** Reduce power imbalance by engaging with young people in non-threatening manners and environments and by employing a lived experience researcher.
 - 7** Value, appreciate, and recognise young people's contributions and reimburse in ways young people want to be reimbursed.

Across October 2019 and January 2020, an average of 15 young people aged 9 to 15 attended a series of four workshops. Each workshop lasted an estimated 1.5 hours and centred on various topics. Follow up interviews were conducted with four young people who provide care to further explore topics and ideas raised in workshops.

Refer to Table 3 for specific workshop details.

Table 3: Workshop details

Let's talk about... change! (2 October 2019)

An educational workshop where young people learnt about the National Carers Reform and current/future support services available to them.

Let's talk about... YOU! (7 October 2019)

An educational workshop where young people learnt to safely share their stories and lived experience.

Let's talk about... hidden young carers! (16 December 2019)

A narrative style workshop where young people reflected on past experiences and used these to inform others how to identify and navigate being hidden.

Let's talk about... support! (15 January 2020)

A collaborative workshop where young people discussed service-related insights, solution ideas and gaps with Lived Experience Researcher, carers workforce and The Commissioner for Children and Young People.

Other research activities were conducted across 2020 to 2021. These included a youth forum; an online social group; in-person coffee catch ups; and a research camp. Refer to Table 4 for more details.

UCWB's Lived Experience Researcher also connected with the carers workforce and collected observational client data and trends via these connection points.



Table 4: Other research activities

Let's talk about... young carers! (29 January 2020)

A youth forum hosted by four young people who provide care. Young people shared their stories, caring experiences and disclosed solution ideas to funding bodies, policy makers and service providers.

The Caring Conversation (COVID-19 Lockdown in March 2020)

An informal, online forum where young people came together to discuss how their world was impacted by caring and COVID-19.

Coffee Catch Ups (October to December 2020)

In-person coffee catch ups at Plant 4 Bowden to continue The Caring Conversation. A regular group of five young adults attended, including young people from rural and regional South Australia.

The Caring Camp (20 January to 22 January 2021)

A three-day, two-night immersive research experience. The Caring Camp empowered 20 young people aged 15 to 18 to enter, think and in roles of peer educators, co-researchers and policy influencers. Young people hosted Fay Fuller Foundation's Chief Executive, UCWB's General Manager, Carers SA's Executive Manager - Service Delivery and Carers SA's Statewide Young Carers Coordinator, and The Commissioner for Children and Young People. They had a Q&A session with these figures, which turned into a strategic discussion about lived experience driven action for change.



Sometimes you are invisible until someone speaks out. So I'm making it my life mission to be that one person who speaks out, so that someone else can be seen.





Research Findings

Introduction to Findings

As a collective, young people who provide care described caring for a loved one as an 'unfortunate, fortunate experience'. Young people reported having matured, 'grown up' and become more resilient, empathetic and outspoken as a result of caring. However, caring came at the cost of normative youth experiences.

UCWB recognised that the complexity of need for young people were changing. Caring has since shifted from young people 'taking on additional responsibilities at home to help out' to now being 'the only priority in a young person's life'. Young people felt, thought, and believed they were assuming the role of service providers in their day-to-day, leaving them with no time, energy, and opportunity to be a young person.

Young people were providing intimate, personal care, and acting as emotional support for their loved ones.

Young people were navigating complex services and systems on behalf of their loved ones, including systems of mental health, National Disability Insurance Scheme, aged care, Centrelink, and employment agencies.

Young people were working through complicated family dynamics impacted by past negative experiences, trauma, financial inequalities and other social injustices.

As a result, young people who provide care have no time to be young people. They have been considered as carers first, young people second by their family, people around them, service providers and policy makers.

As an organisation, UCWB observed consequences of young people neglecting their youth needs in an attempt to prioritise and address their caring responsibilities. This section delves deeper into four ideas explored with young people who provide care and service providers:

- Lived experiences, youth issues and realities of caring
- Service systems for young people who provide care
- Service gaps and
- A proposed model of care that centres young people who provide care as young people first, carers second.



Realities of Providing Care

Social Consequences

'Caring leaves young people with 'no time to do the most important things when growing up and that's socialising, having fun with your friends and finding out who you are'.

Australian Institute of Family Studies (2017)'s 10-year longitudinal study reported that young people who provide care were more likely to be prevented from participating in social and leisure activities, compared to their non-caring peers [5]. This was consistent with what was heard across UCWB's research activities.

Young people disclosed they were unable to attend social events because of the following reasons:

- Young people were worried about their loved one's health, wellbeing and safety while they were away from home.
- Their care recipients required high level and intensity of care, meaning they had to be in close proximity or 'on call' at all times.
- Young people were unable to afford the cost of social events. Transport was also considered a barrier.
- Others reported not being invited to social events, as they had limited friends and/or friends and peer assumed 'they were unable to attend'.

With the emergence of COVID-19 in South Australia, young people were further prevented from attending social and leisure activities as their care recipients were 'overly anxious' about the pandemic, monitored their movements and did not give them permission to leave home. Most young people felt guilty every time they considered going out, even for essential goods and school. This guilt still exists today, further isolating young people from seeing their friends and living life as a young person. This was quantitatively evidenced in Carers NSW (2020)'s National Carer Survey, where young people who provide care had the second highest rate of social isolation [6].

Through observations, it was clear that limited social participation impacted on self-exploration and identity formation. Across UCWB's research activities, many young people described themselves as 'only a carer' and had limited-to-no insights of what personality traits, hobbies and interests, and strengths and skills make them the person they are.

[5] Australian Institute of Family Studies (2017). The Longitudinal Study of Australian Children: Chapter 5 – Young Carers. <https://growingupinaustralia.gov.au/research-findings/annual-statistical-report-2016/young-carers>


[6] Carers NSW (2020). 2020 National Carer Survey: Summary report. Available online at: <http://www.carersnsw.org.au/research/survey>

In UCWB's storytelling workshop, young people revealed they felt responsible for their care recipient and viewed their health, wellbeing, and safety as a priority above their own needs and were committed to doing whatever possible to ensure that they were maintained.

They felt disempowered to pursue anything outside of caring: from higher education to part-time jobs and to extracurricular activities.

They were also not exposed to, presented with, or given opportunities to explore alternate perspectives and narratives that said otherwise and refuted this - even when they came into contact with service providers and other young people in carer groups. As a result, a population of young people who do not see a life outside of caring exists.





You jokingly call us kiddos... but deep down inside, I really appreciate because we are 'kiddos' and we don't get time to be kiddos.

Complicated Family Dynamics

Caring often creates unique and lasting bonds between young people and the person they support. However, caring also complicated family dynamics [7].

Young people reported having strained relationships with parents as they had to 'go behind their parents' back, contact service providers and tell them what was going on at home'. This created tension, distrust, and further complicated parent-child relationships. However, young people believed that 'it was for the better'.

Others had strained relationships as parents attempted to infantilise them and treat them as children. Young people emphasised their position as a young person in these relationships – not a child – and reported parents being cared for struggling to navigate this. Young people felt they were 'technically more of a parent in their relationships than their actual parents' and expressed that it was a difficult space to be in.

Young people also described there being a 'fine line' between the 'parent role' and the 'caring role'. Young people felt they took on a parent role when it came to their younger siblings. This meant that young people who provide care were the ones nurturing their younger siblings, the one ensuring their basic needs were being met and 'the first point of contact when things went wrong at school'. While young people loved their younger siblings, some resented the situation they were in, 'acted out' and further strained relationships with their parents. This was considered a normal and valid response to having their normative youth experiences taken away due to caring and parenting responsibilities [5].

Relationships with other family members were also negatively impacted. Young people reported having strained relationships with siblings, with some indicating they did whatever they could to receive attention from their parents (the care recipients). Young people unconsciously 'compared and kept score' of what they did in the day argued over this. Young adults who provide care indicated that family members undermined and intervened with their decision making even when they had designated primary carer rights. This resulted in many disengaging and disconnecting from their family.

[7] Department of Social Services (2002). Young Carers Research Project: Final Report. Available online at: <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/young-carers-research-project-final-report?HTML>

It's hard missing out on things that other people my age do. Sometimes I blame her for not letting me live my life but I have to remember that she didn't ask for this. She didn't ask to be unwell.



Impacts on Education & Future Thinking

Caring left young people with no time, energy, resources and opportunities to be students and to see possibilities that exist outside of being a full-time carer.

The 2016 Census reported key statistics demonstrating education-related consequences when it came to youth caring. These included:

- Young people who provide care were less likely to complete Year 12 or its equivalent in Australia, compared to their non-caring peers.
- Young people who provide care were more likely to live in a household with lower income (less than \$800 per week), compared to their non-caring peers. This impacted on access to resources and opportunities related to education [2].

Australian Institute of Family Studies (2017)'s 10-year longitudinal study also reported that young people who provide care have substantially lower levels of academic achievement, compared to their non-caring peers [5].

Young people who provide care identified disadvantages they have when it comes to education, providing qualitative evidence of key statistics mentioned above. At the Caring Camp, young people spoke about the academic divide between them and their peers. They felt their financial situation contributed to the divide the most. From their perspective, having laptops, access to Internet and after-school tutors were considered standard among every student in South Australia. As a result, young people who provide care felt disempowered and disadvantages with their education as 'they didn't even have the minimum to succeed'.

Young people viewed schools, teachers and staff, and peers not having knowledge and understanding of youth caring as a disadvantage. Some young people felt that schools did not believe them when they self-identified. They also felt that staff disregarded their caring role and how it impacted on their education; and teachers provided no alternate and/or additional supports.

These young people felt isolated, alone, and withdrawn from their school community, as a result. They fell behind with their school work and were often negatively stereotyped by their teachers as 'poor performing students' and treated as such. These young people were not encouraged to see a future in their education and as a result, disengaged early.

Alternatively, some young people had supportive schools, teachers and staff who negotiated for alternate learning arrangements. Schools, teachers and staff also played an active role in educating their peers about youth caring and connected in with service providers to do more to help. These young people felt better at balancing their roles as students, young people and carers, as a result of this and attributed flexibility, empathy and understanding as contributors their academic success.

Time and energy were also considered disadvantages. Young people were exhausted by their caring responsibilities and this impacted on their ability to focus and perform, to do school work, or to engage in extracurricular activities to find their passions and interests. Others reported missing weeks, months, and terms of school when care recipients' conditions progressed, levels of care became higher and demands became more intensive. When reflecting on these experiences, many young people described that caring made it 'near impossible' to view education as a priority. Young people expressed these experiences 'put things into perspective' and 'makes you realise that you will never be able to do anything outside of caring'.

Caring not only impacts on education in the moment. It impacts on young people's reflections of their own academic capabilities, their ability to think and invest into their future, and to see a world outside of caring.



I feel like I am doing a medical degree, nursing degree, law degree and a social work/psychology degree at the same time. I have to learn to speak in their language because they can't come to my level and speak to me.



Navigating Complex Services & Systems

'Navigating services and systems is difficult for people older than us and people who work within them. Imagine how difficult it is for a young person to navigate these... Well, I don't need to imagine because that's what I'm doing right now'.

Young people caring for their parents noted the strongest pain point in service interactions was not being heard, listened to and consulted with. Young people disclosed service experiences where they did not report their perspectives, were not informed about what was going on and involved in decision making.

Young people caring for their parents explained that parents 'overpowered' them in service interactions. Young people caring for siblings indicated that parents were 'almost always' present in the room during service interactions.

Some parents presented overly optimistic and skewed perspectives to 'downplay the situation' to prevent their parenting practices from being challenged and intervention from child protection systems. Other parents presented more negative perspectives as they felt 'they were more likely to get help if they presented with more pressing and crisis-driven issues'. This meant that care recipients' conditions progressed and worsened as care teams were not presented with the 'true story' and not deriving relevant care decisions. As a result, care recipients became more dependent on young people, further adding to their care responsibilities and leaving them no time to be a young person.

Young people felt ignored and spoken down to when navigating systems. Many young people were told 'they were too young to care' and were pitied by service providers who they presented to. Time in service interactions were spent challenging, undermining, questioning and disrespecting young people and their caring capabilities, rather than supporting them as young people and/or carers.

Young people also spoke about the unspoken rules and grey areas that further complicated systems navigation. 'There was no one way to navigate systems'. What worked for one young person was not going to work for the next. Young people were frustrated by this and the specific intricacies that made the system ineffective for people who needed it the most. Time spent navigating complex services and systems comes at the cost of their youth needs and taking care of themselves, in addition to care recipient's health, wellbeing and safety.

So many people in the health system have told me that I'm too young to be a carer. Well reality check, you don't get to choose an age of when you want to be caring for someone.

DECD / Educate
SCHOOLS
- SW / MH TEAM
- pastoral
- ...

CCYP
other commissioners THE SYSTEM

FAMILY
parents

MPs
advocates
- local ministers

workers
who don't listen
to us


THE 3 WHYS

- Underresourcing?
- Why was there a ...
- how do we navigate life ...
- why is interhal + ex ...
- how do we address an ...
- engagement?
- why does connect ...
- What about a YC ...
- How do we sup ...
- What can we do ab ...
- what about outreach ...
- what is the role of a ...
- What platform does ...
- why not a roundtabl ...





Service Systems for Young People Who Provide Care



From your point of view, caring's the hardest thing in my life but in reality, it's the guilt you feel when you're trying to be a kid and the unknown when it comes to living life like a kid. It sounds stupid to say, but I need help being a kid, more than I need help being a carer.

Prior to National Carers Reform

The Young people first, carers second Research Project occurred in parallel with the National Carers Reform. UCWB had a unique opportunity to gain insights into young people's experiences through this service reform - from both a research and service lens.

Prior to the National Carers Reform, Commonwealth-funded organisations addressed consequences of caring: social consequences, education-related inequalities, complex family dynamics and systems navigation - through one and/or more services (see below).

1 Providing education-related brokerage that involved once-off packages and ongoing financial support for young people who provide care, in addition to the Young Carers Bursary.

2 Facilitating school holiday programs and providing respite options.

3 Providing individualised support through case management.

Service Engagement

Young people's service journey started with carer services initiating contact with them. Some young people were referred straight into case management, where they engaged in an intake process and then allocated resources, support, and other service options. Others undertook a basic intake process and were directed to brokerage services. Others were directly registered onto lists for school holiday programs. As a collective, young people described their service journey to be different and to be inconsistent.

Service Offerings

Service offerings strongly focused on addressing education-related issues and barriers that arose from youth caring. Brokerage services were highly appreciated and were described to 'alleviate financial burdens in the moment'. Once-off and ongoing financial supports were not applicable and relevant to addressing longer term financial inequalities that existed within family units.

Young people wanted to take ownership of their financial circumstances, be 'less reliant' on income support systems and wanted support with becoming more financially independent, as individual people.

School holiday programs provided respite from caring, time to be a young person and enabled young people to connect with others they met through carer services. Young people did not need to worry about the health, wellbeing, and safety of their care recipients, as care arrangements were made by service providers. In addition, young people were not required to justify to parents 'why they wanted to go out and socialise', as service providers contacted parents on their behalf and had 'those, often difficult conversations with them'. A limitation identified by UCWB was the facilitation and coordination of school holiday programs with a carer lens.

While UCWB acknowledges that these programs build connection, confidence, and social skills within young people, it limits their social interactions to others who grew up within carer services and systems; the known carers workforce; and other people within the carer system. Such programs do not encourage young people to diversify their social networks by interacting with others outside of these systems.




Case management for young people who provide care centred on information provision, navigating the wider system, and connecting young people with other relevant services. While case management reduced caring burdens, it prioritised young people's caring needs instead of their youth needs. This was evidenced in young people's service journey where:

- Needs and intended client outcomes were defined within a carer framework
- during intake, as a carer-specific assessment tool was implemented.
- Carer-specific assessments were utilised as a post-intake goal setting and planning tool and were used to review progress.
- Resources, supports and options were allocated based on the level and intensity of young people's caring responsibilities. For example, primary carers
- were prioritised above those who provided low to medium levels of support.
- Referrals were primarily to other carer organisations who supported young
- people as carers.

Service Reform

Organisations that delivered such services were defunded and reformed through the National Carers Reform. In-person supports and generalist brokerage services are now the responsibility of regional delivery partners in the Integrated System of Carer-Specific Supports and Services (ICSS) model in South Australia.



A person is rappelling down a thick black rope. They are wearing a bright orange helmet with a small logo on the front, a black Champion hoodie with the Champion 'C' logo repeated all over it, black pants with three white stripes down the side, and black sneakers with a white swoosh. The background is a clear blue sky with some blurred green foliage at the bottom.

We haven't lost lives to caring but we have lost souls of young people because of caring. We can't let this continue. We won't let this continue because if it does, you lose your next generation of brilliant minds with great ideas... kindhearted people with empathy... do I need to continue?

Current Services for Young People Who Provide Care

The National Carers Reform transformed the carers landscape and aimed to create a more standardised service experience for carers across Australia. From August 2019, organisations – with a successful outcome in the nationwide bid for the ICSS model – were named the lead regional delivery partners (RDPs) and actioned on mandatory requirements outlined in government directives. RDPs engaged in the following actions:

- Assumed the operations of Carer Gateway in their designated service areas.
- Became the centralised contact and access point into carer services. On a more operational level, engaged carers – registered with Carer Gateway – in an intake process and complete a carer-specific assessment (Outcome Stars' Carer Star) to determine priorities and needs.
- Allocated resources and supports based on identified priorities and needs.
- Distributed Direct Carer Support packages, provided in-person peer support for carers and linked carer with national online and phone-based services.

On systemic and operational levels, young people who provide care stated they were not recognised, treated, and supported as carers before, during and after the National Carers Reform. This remains a problem, with all young people reporting the following service journey in Image 2.



Image 2: When presenting to current services

Recognition (how young people are recognised as they present to a service)

- Young people were externally identified as a carer and were directed to call and register with Carer Gateway.
- Alternatively, young people self-identified as a carer and engaged in a self-initiated process of calling Carer Gateway's 1800 number for support.

Treatment (how young people are treated)

- Assessors were trained to filter young people's needs through a carers lens and conducted intake assessments with young people based on Outcome Stars' Carers Star.
- While this assessment focuses on other life domains, assessors prioritise carer-related impacts.

Supported (how young people are supported)

- Young people were allocated resources and supports based on Carers Star and received Direct Carer Support packages and in-person support that still considered young people as carers.

Outcome (how young people are when they exit)

- Young people were re-engaging and re-presenting to carer services with more pressing, crisis driven and long term issues.

In the ICSS model, young people were observed to re-engage and re-present to carer services with more pressing, crisis driven and longer term issues. Young people provided explanations as to why this occurred:

- Carer services were not equipped to inquire and respond to issues young people who provide care were facing.
- Carer services were operated by workforces with limited knowledge, skills and experience in working with youth.
- Carer services and systems were not designed in consultation with young people or with their best interests in mind.
- Models of care for older carers were applied to young people who provide care.
- Underlying issues were not detected at intake and as a result, not resolved or managed by carer services.
- Limited-to-no follow ups and check ins with young people, meaning there were limited opportunities to identify and address underlying issues or issues as they were emerging.
- Appropriate and relevant referrals to other services were not made or not followed up on.

Service delivery workforce identified additional reasons. These included:

- Young people were not comfortable with disclosing private information and lived experiences over the phone, meaning that presentations at intake were not realistic and accurate depictions of their experiences and what young people required support with.
- Carers Star was selected as the assessment tool to be used within Carer Gateway. Carers Star was designed for adult carers and had to be adapted to be used in a youth caring context. It is recommended that My Star is used for carers under 18, as it is youth specific and centres on eight life domains relevant to children and young people [8].

[8] Triangle Consulting Social Enterprise Limited (2021). Carers Star – The Outcomes Star for people caring for others. Available online at: <https://www.outcomesstar.org.uk/using-the-star/see-the-stars/carers-star/>.



Service Gaps

Carer organisations implemented the National Carers Reform without addressing young people's youth needs. Carer organisations were not at fault for this. In fact, this was an oversight by the sector who systematically misunderstood who this cohort of young people were, what they experienced and how their youth needs were impacted by caring. As a result, service gaps existed within the ICSS model, further validating that young people who provide care were not best placed and/or supported in a carer system. Service gaps were identified in collaboration with young people who provide care and service providers. Gaps varied depending on age and hence, will be documented as such below.

Under 15

Children and young people aged under 15 identified the following as service gaps:

- No service response for children and young people under 13.
- No alternate arrangements, or outsourcing of services, being made for this group. As a result, children and young people under 13 were discharged from previously Commonwealth-funded carer services and not accounted for moving into the Reform.
- Service needs were identified as social opportunities; respite options; early intervention supports (i.e. education and sense making); and in-home supports for care recipients.

Between 15 to 18

Young people aged between 15 and 18 identified the following as service gaps:

- Brokerage models were insufficient at addressing emerging and evolving youth issues stemming from mental ill-health, loneliness and social isolation; unemployment, financial insecurity and food instability; homelessness; and/or academic disengagement and lack of future direction.
- Limited opportunities for self-exploration, identity formation and career exploration existed.
- Limited-to-no in-person support existed in South Australia (at the time of this research was conducted)
- No crisis response outside of Triple Zero and Mental Health Triage. Problems faced by young people were 'not severe enough to contact these numbers' or could not be addressed by these agencies (i.e. heating being turned off, eviction and inability to pay bills).

- No support with crisis management and emergency planning for young people facing more pressing and crisis-driven issues.
- Service needs were identified as peer support and social opportunities; respite options; crisis management and emergency planning; mental health support; support with education, employment and independent life skills; and in-home support for care recipients.

Between 18 to 26

Young adults aged between 18 and 26 identified the following as service gaps:

- No age-specific services were available to young adults, with young adults reporting experiences of being merged into services and support options for older carers (aged 60 and above).
- Limited efforts existed to re-engage young adults who fell through the gaps since the National Carers Reform.
- Limited access points to young adults existed after they leave an education system.
- Young people had limited-to-no supports to navigate physical, emotional and social consequences when care recipients pass away. Consequences included navigating loss and grief, not being a carer, and wills, debts, life insurance and other assets.
- Young people had limited-to-no support to aid their transition away from home and caring and into independence.
- Service needs were identified as employment support; assistance with pursuing higher education or vocational opportunities; crisis management and emergency planning; support with transitioning into independence and moving away from home; support with grief, loss, bereavement and other consequences.



It's not too late to bring young people on the journey - whether this is a transition and engaging with us then, or designing and developing a service and asking us what we want. Don't make the mistake of not doing this just because you think it's too late. It's better late than never.



Proposed Model of Care

Young people's service experiences demonstrated that carer services, organisations and systems were not best placed to support young people who provide care. Service gaps and needs outlined in the report emphasised the neglect of young people's youth side when it came to service provision; highlighting the role of mainstream youth services in supporting young people who provide care.

Moving forward, young people want to be recognised, treated and supported as young people first, carers second. While this does not eradicate the issue of unpaid caring in South Australia, this statement allows young people to prioritise themselves, take care of themselves and be supported to see and live a life beyond caring. While it is changing to 'reform a reform', service providers must start by embedding small changes into their individual practice to make this statement a reality and for young people who provide care to have better outcomes and better futures.

Service providers from mainstream youth services and carer services can stay true to this statement through four actions.

- 1** Placing young people at the centre of service provision and prioritising their needs, goals, and outcomes.
- 2** Giving equal weight to their youth and caring needs and recognising that in some instances, one may be more taxing than the other.
- 3** Working collaboratively with young people, with other service providers and the wider sectors.
- 4** Having the best intentions and interests of young people in mind.

How this looks like in practice is documented in service journeys outlined in Image 3.

Image 3: Service journeys based on proposed model of care.

When presenting to youth services

When presenting to carer services

**Recognition
(how young people are recognised as they present to a service)**

- Young people present to a youth service in need through self-referral or external referral from other generalist and carer services.
- Alternatively, service providers reach out to young people in youth access points and identify young people who are in need of support.

- Young people presenting to Carer Gateway through self-referral or external referral from other generalist and youth services.

**Treatment
(how young people are treated)**

- Service providers conduct holistic youth assessments, using a conversational approach to gather contexts. Questions related to caring are asked but the initial conversation does not centre around caring.

- RDPs conduct Carers Star and are encouraged to delve deeper to gather information and context surrounding the young person's situation.
- RDPs determine what needs can be addressed through carer services and what must be addressed through follow up referrals.

**Supported
(how young people are supported)**

- Service providers provide youth specific responses. These include individualised supports and tailored referrals to achieve positive outcomes within:
- General health, mental health and wellbeing.
- Employment, financial insecurity and housing stability.
- Academic engagement and future-orientated thinking.
- Planning and managing crises and emergencies.
- In addition to in-person peer support with young people (not limited to young people who provide care).
- Where applicable, young people are encouraged to register with Carer Gateway to receive Direct Carer Support Packages.


- RDPs distribute Direct Carer Support packages where they see fit. RDPs encourage young people to seek additional help through referrals.
- If young people consent to being referred, RDPs action on these referrals and connect them into youth services.

**Outcome
(how young people are when they exit)**

- Young people are recognised, treated and supported as young people first, carers second.
- By having both their youth and caring needs addressed, young people are enabled and empowered to thrive and reach their fullest potential.



Recommendations

A person wearing a black helmet and a black harness is ziplining through a dense forest of tall, thin trees. The person is suspended in the air, holding onto the zipline rope. The background is a clear blue sky. The image is used as a background for text boxes.

How do we deal with the guilt we feel when we are trying to live our own lives? How can we communicate our needs to our parents? How can we have difficult conversations about the future? How can I move out after I'm 18, but still make sure mum is supported?

How can I just live life as a young person, not as a carer? Please tell me how...

Policy Recommendations

The following policies are recommended to support UCWB's endorsement of recognising, treating, and supporting young people who provide care as young people first, carers second.

- 1** Young people who provide care must be recognised, supported, and treated as young people first, carers second.
- 2** Systemic re-definition and re-thinking of who young people who provide care as, what they do, what they need and what their problems are must occur.
- 3** Shifts must occur across the sector.
 - Carer services must acknowledge that they are part of the solution, but not the only solution.
 - Mainstream youth services must recognise young people who provide care as 'young people in need' and respond to them as such.
 - Generalist services must acknowledge their role in supporting young people to access to mainstream youth and carer services.
- 4** Young people who provide care must not be siloed into one system: carers system or youth system.
- 5** Collaboration must occur across the sector to ensure better outcomes, better opportunities for change, and better futures for young people who provide care.

Practice Recommendations

The following practices are recommended to support UCWB's endorsement of recognising, treating, and supporting young people who provide care as young people first, carers second.

- 1** Every young person who is registered with Carer Gateway receives youth-specific response and/or referrals, in addition to carer-specific support.
- 2** Every young person who provides care and presents to a youth service is responded to as a young person in need.
- 3** Every young person who provides care and presents to a service must not be siloed into being recognised, treated, and supported as either a carer or a young person. Services must take a holistic approach.
- 4** Service providers must review their intake process and make it more inclusive of young people who provide care. How this looks like in practice includes:
 - Youth services can embed questions around caring into their intake assessment and explore how caring impacts on them as a young person and their ability to be a young person.
 - Carer services can expand their focus beyond caring and gather contexts about other underlying issues existing in a young person's world.
- 5** Services should recognise the importance of peer and social support, among other needs described by young people who provide care.
- 6** Services should evolve and emerge with the needs young people are presenting with.

7 Services should be flexible to respond to youth-related needs and the complexities of being a young person who provide care.

8 Investment into ongoing education, training and professional development is needed across various workforces. This includes training for:

- Carer services to respond to young people who provide care, using a youth centric approach.
- Mainstream youth services to be aware of how caring influences the challenges young people face and are presenting with.
- Generalist services to identify, recognise, and support young people who provide care through referrals. '
- Teachers and other school staff to recognise and identify young people who provide care and to provide them with relevant service information to direct young people to access services.



Conclusion

Caring is a part of a young person's life but it is not everything. Young people who provide care want to shift the focus and are calling to be recognised, treated, and supported as young people first, carers second.

They want to experience life like other young people around them. Whether this is hanging out with friends; navigating their own identity and reflecting on what makes them 'them'; focusing on their studies and/or thinking about future possibilities – young people want to, strive to, and have the right to experience.

There is significant work to do across services, systems and the sector in order for young people to be recognised, treated, and supported as young people first carers second. We hope that our research acts a starting point for youth and carer sectors to come together and to work collaboratively to honour the experiences, perspectives and solution ideas of young people who provide care.

Moving forward, UCWB commits to taking on these findings and incorporating them into the organisation's service and advocacy actions.

UCWB commits to continuing to provide a platform for young people who provide care to be heard, to be listened to, and to have a voice of change.

UCWB will fight tirelessly for young people's lived experience-driven wisdom to be translated, actioned, and embedded into practice.

As an organisation, UCWB encourages service providers to do their part, to care, and to ensure that young people who provide care are recognised, supported, treated and cared for as young people first, carers second.



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Featuring the stories of
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 Chiara • Danielle • Elanna • Elijah • Eliza • Elliot
 Emma • Felicity • Finn • Georgia • Hanna
 Jacinta • Jasmin • Jeremiah • Jessica • Karlee
 Loki • Luke • Mahalah • Mikayla • Natasha • Nicole
 Noah • Riley • Sophie • Sophie • Terri • Truc
 Tyron • Valentino • Wayne
 + other young people who did not wish to disclose their names

**If you have any
 questions, please
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