Young People with Caring Responsibilities: Time for Action

Summary Research Findings, Policy & Practice Recommendations

The Bouverie Centre, La Trobe University

Acknowledgement of Country

We acknowledge the Wurundjeri People of the Kulin nation as the Traditional Owners and Custodians of the land on which we work. We recognise their continuing connection to land, water and community. We pay our respect to Elders past, present and the emerging leaders of the future.

Recognition of Lived and Living Experience of Caring Responsibilities

The Bouverie Centre recognises people with lived and living experiences as consumers, family members and young people with caring responsibilities, including those who have gone before us. In being informed and driven by the voices and collective wisdom of those with lived and living experience, we can create meaningful change to strengthen identification, engagement, referral pathways and support services for young people with caring responsibilities in their families.

Authors' Acknowledgements

The Bouverie Centre's researchers and project members from the Satellite Foundation warmly thank the participants in this research. This is a many-fold group: young people with caring responsibilities, adult family members with lived and/or living experience of psychological distress through mental illness or substance use concerns, professionals and service providers. Within the Bouverie Centre, we thank our lived experience team members, and our young person with caring responsibilities for joining us to both inform the project and learn new research skills. All contributors generously shared their experiences, views and aspirations in strengthening identification, engagement, referral pathways and access to support services to better meet the needs of young people whose home life includes caring responsibilities. This research was successfully shaped by the voices of lived experience.

Introduction and Context

The Victorian Department of Health

The Victorian [Department of Health](#) (Department) plays a critical role in the state's health system and aims to deliver and sustain a world-class health care system that leads to better health outcomes for all Victorians. The Department's Mental Health and Wellbeing Division (MHWD) leads the promotion of good mental health and wellbeing in the Victorian community and the prevention and reduction of psychological distress and harm associated with substance use and addiction. This includes overseeing the delivery of the Royal Commission into Victoria's Mental Health System recommendations (Royal Commission). Central to the work of the MHWD are the perspectives and preferences of people with lived and living experience of psychological distress or mental illness, substance use or addiction, and those who support or care for them.

In 2021, the Royal Commission into Victoria's Mental Health System[1] developed [a set of recommendations](#) for mental health and wellbeing system reform and redesign. Specifically, Recommendation 32.3 of the final report recommends that the Victorian Government "strengthen identification and referral pathways for young carers through the mental health and education systems". In this context, young people are defined as those under 25 years of age, with caring responsibilities for a family member/s experiencing psychological distress, mental illness, substance use or addiction.

In 2023, the MHWD commissioned the Bouverie Centre of La Trobe University, in partnership with the Satellite Foundation, to scope existing international research and conduct local field studies on identification and referral pathways for young people whose home life includes caring responsibilities for an adult with mental health, alcohol or other drug (AoD) challenges. This follows a scoping project, commissioned in 2022, by the Department of Education who engaged *dandolopartners* to scope existing and required supports for young people in the school context (http://www.dandolo.com.au/).

The Bouverie Centre of La Trobe University

The Bouverie Centre is an integrated practice-research centre of La Trobe University and a Government funded state-wide provider of family therapy interventions. It plays a key role in the development and dissemination of family-oriented ways of working when in the mental health arena. It also coordinates the FaPMI program (Families Where a Parent Experiences Mental Illness) across Victorian Adult Mental Health and Wellbeing Services. The Bouverie Centre's research program aims to understand how relationships and circumstances affect people's abilities to develop well, to care for ourselves and others, and to manage challenging times, at all stages in family life, in all cultures, for all people. To achieve these goals the research team works closely with a range of stakeholders.

---

[1] https://finalreport.rcvmhs.vic.gov.au/

The Satellite Foundation

The Satellite Foundation is a not-for-profit organisation that connects and empowers children and young people, where a family member experiences mental health challenges. Satellite aims to foster a strong connection between young people, their families and the wider community. Its many programs combine creativity and the sharing of lived experience to combat isolation and promote confidence, self-esteem and good coping strategies in young people with caring responsibilities. Satellite offers peer support in a range of in-person and online programs, workshops, activities and projects that are centred on connection.

Project Scope and Objectives

This project aimed to provide evidence enrichment to inform continuous improvement of identification and support for young people in the context of adult mental health and wellbeing services, and alcohol and other drug services. To do this, we took a two-phase approach:

a. **Rapid systematic literature review.** This part of the project aimed to scope international best practice evidence for identification, engagement, and supports for young people – formal and informal – whose home life included caring responsibilities for family member/s experiencing mental health and/or substance use challenges. Led by one of Bouverie's lived experience consumer researchers, this part of the project was assisted by our young person with caring responsibilities academic, who was trained in the methods of extraction and synthesis and contributed to the interpretation of findings.

b. **Consultations.** Multiple consultations with young people, family members and mental health practitioners were conducted. A team of researchers, led by qualitative specialists and centrally including our young person with caring responsibilities academic, designed a stepped enquiry into the variety of lived experiences and meanings of caring responsibilities for young people, then moved to systematically explore barriers and enablers to identification and referral pathways, to better recognise and bring young people into contact with supports and services.

Continuous Input of Lived and Living Experience

Central to this project is the engagement and voice of a diverse range of young people in caring roles, family members, non-government organisations (NGOs) and government stakeholder perspectives. Their perspectives are represented in the findings of the field studies. Moreover, the design and execution of the research studies was continuously informed by the Bouverie Centre's three Lived and Living Experience (LLE) Carer and Consumer Researchers, and a partner Carer Academic from La Trobe University. The rapid review was led by a lived experience consumer academic (JO) and a carer academic (HK) and supported by the Centre's full research team (see Appendix A, page 3).

Most importantly, the project integrated the work and views of a Young Carer Academic (SD). The Bouverie Centre's research team worked with the Satellite Foundation to engage a young person with current caring responsibilities (SD), who worked with the team at the Centre over three months, and

helped shape the design, analysis data, and recommendations. This mentoring experience was a unique knowledge exchange, both an opportunity for our team to learn from and with this young person, and for the young person to be mentored by a range of researchers in study design, data searching, synthesis and reporting.

In a knowledge exchange exercise, the Young Carer Academic was taught many of the academic methods involved in systematic reviewing, and in turn contributed to the interpretation of findings and to the design and execution of the field studies.

Ongoing collaboration was enabled through weekly meetings with our LLE advisors and stakeholders, including the Department's Lived Experience Branch, ensuring input into design, field work, analysis to write up and the finalisation of recommendations.

The following sections provide a summary of key findings. Extended appendices provide the details of lived experience input across the project, literature review and the consultations.

Research Purpose and Design

This rapid review focused on young people with lived and living experiences of caring responsibilities for a family member/s experiencing psychological distress, mental illness, substance use disorder or addiction. Objectives were:

- Evaluating barriers, gaps and opportunities to identification and support within and between mental health, AoD, education, and employment service systems

- Identifying commonalities and differences in practice between varied support services.

- Exploring the effectiveness of the various identification, engagement, and referral methods, when outcome data is accessible.

Rapid reviews use "abbreviated" systematic review methods to generate evidence in a short time. The present review was conducted in accordance with the Cochrane Rapid Review methodological recommendations and the Joanna Briggs Institute methodology framework. (Aromataris & Munn, 2020). The search protocol has been registered with the PROSPERO repository (CRD 42023446988). Appendix B (pages 5 – 10) provides methodological details including information on eligibility criteria, search strategy, information sources, study selection, data extraction and quality appraisal.

Co-development of Literature Review

Collaborative development of search terms occurred in discussion with the Satellite Foundation and the Victorian Department of Health. Further refinement continued until the search terms were agreed by all parties. The Young Carer Academic (SD) contributed to conducting the review and analysing the results, supported by a lived experience consumer academic (JO) and a carer academic (HK). To enhance the review's relevance and integrity, results were jointly interpreted with our partner organisations and the contributing young person (SD).

Summary of Key Findings

PART A: Summary of Rapid Systematic Review

Extended appendices provide the details for this review (see Appendix B, pages 11 – 35). Below, we provide a summary of key findings.

About the Review Method and Included Studies

Published studies between 2013-2023 were searched across four databases (see Appendices for full search terms and databases). The team screened 5,413 unique studies, 26 of which were eligible and included in this review. Following data extraction, study quality (risk of bias) was assessed using the validated Mixed Methods Appraisal Tool (MMAT; Hong, 2018). While a rapid review does not necessitate an assessment of study quality, the strength of recommendations provided is enhanced by it.

Among the 26 included studies, 14 were qualitative, six were quantitative and the remaining six were mixed methods in design. Only four were longitudinal, with the remainder cross sectional or short-term, pre-post outcomes. All participant data were in the form of self-report measures.
Only one study was conducted in Australia (McDougall et al., 2018), while the majority (88%; $n= 23$) originated from European countries, whose practices in this area are advanced. Similarities of context that suggest applicability of overseas findings include the publicly funded nature of the service systems studied and the age and experience of caring for young participants. Differences may include culturally specific contexts that impact MHWB and AoD service delivery. For example, in Northern Europe, progressive models of mental health care are evident, such as the Open Dialogue method, with strong attention to lived experience, which are emerging but as yet not widely implemented in Australia (Dawson et al, 2021).

The included programs varied widely in content, delivery mode, duration and facilitators involved, making direct comparisons of different supports and their efficacy difficult. The aims ranged from examining the generic experience of support through to the impacts of particular activities on well-being. Some studies contrasted web and in-person supports, predictors of coping and the role played by illness type, relationship to family member and nature of caring responsibilities (as detailed in the Appendices). Intervention length ranged from five days to eight months (M=14 weeks). Programs varied in frequency, ranging from weekly to monthly sessions.

About the Young People with Caring Responsibilities

In our pool of 26 identified studies (see Appendix B, page 8), there was a distinct gender difference in proportion of females identified in caring roles relative to males (69% v 31%). This accords with current and prior global prevalence data in locations such as Australia (Australian Bureau of Statistics, 2016; Cass et al., 2009), Canada (Stamatopoulos, 2015), Europe, and America (Bray, 2012, Fleitas Alfonzo et al., 2022).

Five studies differentiated the person being cared for. Most young people were supporting a parent and of those, most were caring for a mother (mean 73%) (see Figure 1).
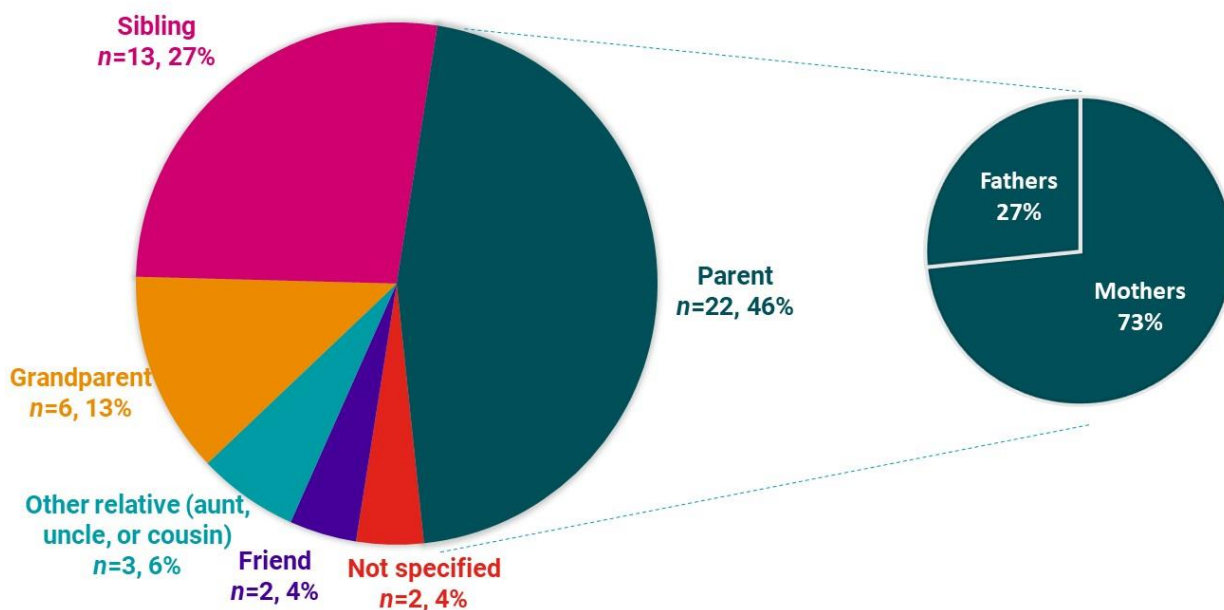
Fig. 1. Care recipient relationship to young person with caring responsibilities.

Of nine studies that examined the mental health status of young people with caring responsibilities, more than half (56%) identified a reduced sense of well-being for the young person linked to their caregiving roles (De Roos et al., 2017; Drost & Schippers, 2015; Waters, 2019; Wepf & Leu, 2022). Nearly half (48%; *n*=108) of young people reported feelings of loneliness (Ali et al., 2015). Young people with caring responsibilities also reported higher rates of physical health challenges compared to non-carers (16% v. 9% for non-carers; Landi et al., 2022).

> **Together, these findings suggests that young men with caring responsibilities are less likely to self-identify as caregivers or less likely to seek or accept support, and that male care recipients are less likely to identify as a parent with care needs. Regardless of gender, a significantly reduced sense of well-being for the young person is common, linked to their caregiving roles.**

Siloed Service Sectors

The majority of supports identified for young people were in the mental health sector. A much smaller number focused on education. No data was found for the AoD, financial, and employment sectors. Only a small number of studies thoroughly investigated cross service intersections for identification, and referrals. Of the studies reviewed, most identified a problem with services operating independently of each other, and lacking collaboration and integration between service providers. Cross sector touch points for potential identification were rare, with most support only available via the adult mental health service system, rather than integrated school or club based support (Chevrier et al., 2022; Whitley & Wooldridge, 2018).

The resulting challenges of a siloed and disconnected system as identified included: young people not being identified by support systems, fragmented and inefficient approaches to assisting, requiring young people to re-share their caring experiences with each new support service, and service deferral (Fargas-Malet & McSherry, 2018). While there is an emphasis on broader support available to all children with a parent or family member with mental health challenges (like CHAMPS; Reupert et al., 2013; von Doussa et al., 2023), we found a lack of tailored support specifically designed for young people with caring responsibilities.

> **Despite the multiple sectors in which young people with caring responsibilities live their lives, the literature confirms the ongoing universal challenge of siloed service systems, with associated failed opportunity for identification and support.**

Referral Pathways

Only eight studies (31%) reported methods of referral *into* their support service. The referring person was most often the young person (*n*=3 studies), a mental health professional (*n*=3 studies), a parent (*n*=2 studies), a teacher or school staff (*n*=2 studies).

Of the studies that reported on referral method, 38% relied on self-referral from young people. As also found inprior research (e.g., Carers Trust and The Children's Society, 2016), this pathway provides autonomy to seek support when the young person is ready, yet an over-reliance on self-referral methods comes with risks (Radez et al., 2021). Young people often have limited experience with independent help-seeking. In this light, system reliance on self-referral shifts the onus onto the young person and will primarily serve those motivated and proactive in seeking support from already evident pathways (Carers NSW, 2020; Smyth et al., 2011). Self-referral may be hindered by social factors, like stigma, embarrassment, and shame, trust and confidentiality concerns, uncertainty regarding the nature of the role and approachability of health care professionals involved in treating their family member, and a fear of "deceiving" a family member they are caring for.

> **Findings indicate that self-referral remains the common pathway into services. In this light, system reliance on self-referral shifts the onus for identification and support finding onto the young person and will primarily serve those motivated and proactive in seeking support from already evident pathways (Carers NSW, 2020; Smyth et al., 2011). Proactive efforts to identify and inform young people about sources of support are needed to improve awareness of and access to services, especially among harder-to-reach groups.**

Relying on self-referral for young 'carer' support may also imply that the services young people are currently engaged with, such as education providers and sports clubs, may not effectively identify and refer young with caring responsibilities to the essential support services they require.

Systemic Barriers to Accessing Support

Many studies detailed the dissatisfaction of young people with the mental health service system's lack of ability to recognise and address their unique needs and situations. Barriers to accessing or sustaining support included long waiting lists, need for parental consent, large group sizes and pragmatic difficulties in attending appointments. Support program staff also detailed their own set of challenges, particularly related to securing funding, and obstacles including obtaining permission from local schools to run young carer programs on-site, and no established mechanism for liaison with teaching staff familiar with the young person. Within the education system, challenges focused on recognising and supporting young people with caring responsibilities, and cumbersome processes involved to request formal assistance. At the community level, no study mentioned public education strategies or neighbourhood awareness initiatives.

The Young Person's Involvement in Screening and Support Design

The review revealed little reliance on screening instruments across all key service sectors tailored to helping young people to describe their unique strengths, burdens and needs of young people with caring responsibilities. One instrument, the *Carers of Older People in Europe Index,* (COPE Index; McKee et al., 2003) has been repurposed for this younger age group but without psychometric validation (Balducci et al., 2008). We note validation processes are unlikely to be essential as the gateway to service access, given the universal criteria is as simple as being a young person in a support role.

Only one study reported the involvement of young people in shaping and designing the support program.

> **There are currently no validated screening tools available to help identify young people with caring responsibilities when their family member enters the support spectrum. Once in a service setting, we found no evidence of sustained support. Most approaches are not tailored to individual context. Current approaches are oriented to addressing immediate or acute concerns. Few studies identified mechanisms for preventative efforts or enduring effects.**

Heterogeneity and The Need for Tailored Responses

A large Netherlands based longitudinal study (DeRoos, 2017) found great diversity in the nature of both the caring role and the young person's individual characteristics. With this, they found associated differences in wellbeing, need for help and nature of the supports used. In the present review, diverse factors contributed to the support needs of young carers, such as the age of young carers, the duration of the family member's illness, the current health status of the care recipient member, the family's structure and the family's available caregiving resources. Needs identified varied from financial aid to educational and mental health assistance, depending on the care recipient's current health status.

Despite this clear diversity, this review found that few services were tailored to a young person's circumstances. Most detailed a predefined, standardised support framework of offerings. In three studies, program activities were selected for the young people based on their unique needs and experiences. Two studies involved both standardised and personalised support, with one designing an individual program uniquely for each young person. Outcomes between methods of support were not reported. Most studies (96%; *n*=25) showed that support was only provided over the program duration, without consultation about or provision of post-intervention or follow-up support. This lack of sustained support and support re-engagement was identified in most studies as a serious limitation, with negative impacts for young people and concern for sustained efficacy of the support provided. Identified supports do not appear to align with the long-term nature of mental health challenges or age-of-onset concerns.

> **The evidence review showed a dearth of models that paired the circumstance of the young person to methods of identification, referral pathways and service supports. There is little reported evidence of ongoing and interconnected support systems that address the young person's enduring and changing developmental needs over time, within their family's unique and dynamic context. Current service systems are reliant on standardised and time-limited supports. Findings suggest young people with caring responsibilities could both be identified earlier in their caring journey and accompanied by tailored services throughout it.**

The Research Gaps

The state of evidence for support frameworks tailored to the needs of young people in support roles is in its infancy. There are no established, evidence-based service system level models to draw on. In revealing these gaps, the study highlights key needs for new research into:

- Effective strategies in the mental health and AoD sectors that enable cultural change and practice reform necessary for routine identification of, and engagement with, young people with caring responsibilities.
- A clear depiction of what constitutes good or best practices in support provision, including matching of services to the family and developmental contexts of the young person.
- Nuanced demographics to better identify diverse geographic, cultural and linguistic needs, to allow for customised engagement strategies, sensitive and accessible to all communities.
- The evaluation of implementation strategies and their cross-sector effectiveness.
- Community education initiatives: there is no evidence for effective public health messaging regarding de-stigmatisation of the mental health caring functions of family.
- High level evaluation of future policy initiatives and practice investments are imperative.

In summary, this systematic literature review synthesised recent international evidence on service models and their components for identifying and supporting young people with caring responsibilities. This part of the project provided an essential platform for identifying gaps in the literature and guiding the direction of field studies in Part B.

Part B: Fieldwork Consultations with Young People, Family Members and Practitioners

Extended appendices provide the details for the fieldwork consultations with young people, family members and practitioners (see Appendix C, pages 36 – 45). Below, we provide a summary of key findings.

Research Purpose and Design

A qualitative research methodology was used to compliment the rapid review methodology of Part A. Our focus was on capturing three perspectives on the experience of young people living within the world of family mental illness: the child, the family member, and the service provider. The approach acknowledges that participants are experts on their own lives, and their contributions to the development of new knowledge are key. We aimed to hear from:

1. **Young People** about their thoughts and feelings about their caring roles and responsibilities, knowledge of services and avenues into them, and the supports they received or would have wanted. Sixteen young people participated. They were between the ages of 14 to 25 years old, living in Victoria, with caring responsibilities, connected to formal services (*n*=10) or not connected to any formal services (*n*=6).

2. **Affected Family Members** with lived and/or living experience of psychological distress, mental illness, substance use and/or addiction about the young person's needs, service access and recommendations for system change. Six family members aged 18 and over participated.

3. **Practitioners within Victorian Adult MHWB and AoD services** about their professional intersections with young people and ideas on how to strengthen identification, referral pathways and support services. Thirty-eight practitioners took part.

Co-development and Facilitation of Consultation Sessions

The Bouverie Centre partnered with the Satellite Foundation (Satellite) to design the semi-structured interview guide and facilitate the consultations with young people and adult family members. Primary domains of enquiry were co-determined with all stakeholders as follows:

- Lived experience and meanings of caring responsibilities
- System and cross-sector awareness of young people with caring responsibilities
- Barriers, enablers and future vision:
- Identification and recognition
- Referral pathways
- Support and services

Ethics, Recruitment and Engagement Strategies

All phases of consultation were conducted with ethical approval by the La Trobe University Human Ethics Committee (Ethics Approval Number HEC23347). Engagement approaches for young people were informed by best practice guidelines, child safe standards and child's voice principles. This included age-appropriate and safe methods to engage young people and families, such as peer support and the use of trained lived/living experience youth facilitators from the Satellite Foundation.

Participants were recruited across Victoria via a diverse range of methods, using co-developed participant recruitment flyers and information sheets. Relevant organisations distributed participant recruitment flyers through their networks and newsletters. Researchers also used their networks, snowball and purposive sampling techniques to recruit potential participants.

Adult family members and young people received a gift voucher of $175 for their participation in the consultations, in alignment with the Department of Health guidelines for reimbursing participants with lived and/or living experience. The Bouverie Centre, as the Statewide Coordinator of the FaPMI program (Families where a Parent has a Mental Illness) engaged this network to recruit practitioner participants. Additionally, other organisations such as Aboriginal-led organisations and carer organisations were approached through the Bouverie network. Professionals participated within their work capacity and were therefore not reimbursed for their time.

Young Person Research Partnership

Our Young Carer Academic also worked closely with us on this aspect of the research. The exchange was a powerful sharing of ideas and skills. The young person contributed to shaping the interview guides for the consultations and synthesis of findings. The young person gained research experience within a friendly environment, supported and mentored throughout the process by a senior researcher.

Method

Together, our teams coordinated:

- Two youth-led consultations with young people aged 14–25 years, engaged within the Satellite community and 'carer' organisations. Ten participants had experienced support to date and six had not. These took the form of online focus groups. Online attendance was preferred by most participants and offered a means of gathering geographically diverse young people together at short notice. The forum combined semi-structured interviews with Mentimeter visually based activities to promote accessibility and complement the interview questions.

- Individual interviews occurred with six family members affected by mental health challenges, substance use and/or addiction, living with a young person who offered support to them.

- Individual consultations occurred with 28 practitioners working within a diverse range of settings (e.g., adult mental health and wellbeing services, AoD services, education and organisations supporting young people with caring responsibilities). A further ten participants completed the interview questions in a survey format.

Characteristics of Participants

Table 1 provides a description of participants' demographic characteristics.

Table 1. Description of participants' demographic characteristics

Participants	Basic demographic characteristics
Young people with caring responsibilities (*n*=16) Connected to services *n*=10 Not connected to services *n*=6	Ages 14-25 years old Community and cultural identifications: • Culturally and linguistically diverse (5: 31%) • Aboriginal or Torres Strait Islander (2: 12%) Gender: • Female (9: 56%) • Male (3: 19%) • Non-binary (4: 25%) Other characteristics: • Neurodiversity and/or disability (5: 31%)
Affected family members (*n*=6)	Ages 36-57 years old Community and cultural identifications: • Culturally and linguistically diverse (2: 33%) • Aboriginal or Torres Strait Islander (0) Gender: Female (5: 83%) Male (1: 17%) Family characteristics and role: • Mother (5: 83%) • Father (1: 17%) Living location • Metropolitan home (3) • Regional home (3)
Practitioners (*n*=38) Aboriginal led organisation practice lead (2); Case managers (4); Lived experience workers in 'carer' organisation (4); Secondary school teachers (2); FaPMI Coordinator (14); FaPMI Community Worker for Children and Young People (4); Mental Health Practitioners (5); AoD practitioners (3)	Ages 21-65 years old Community and cultural identifications: • Culturally and linguistically diverse (9: 24%) • Aboriginal/Torres Strait Islander (2: 5%) Gender: • Female (34: 89%) • Male (4: 11%) Work location • Metropolitan (10: 26%), • Regional (28: 74%)

Summary and Key Findings: Fieldwork Consultations

The interviews were audio-recorded, then transcribed verbatim. The transcripts of the interviews were analysed with the aid of the software package NVivo to enable grouping of convergent themes and divergent themes across participants (Lutz & Hill, 2009). Thematic analyses followed six phases of thematic analysis (Braun & Clarke, 2006). See Appendix C, page 36 for details and elaboration on the analytical methods.

Lived and Living Experiences of Caring Responsibilities

We first asked young people to situate us in their dominant experience of their family context. Responses were diverse, from the positive "*loving*" to the difficult "*unloving*", "*traumatised*" and "*psychotic*", to the complex "*messy*", "*wonky*", "*bonkers*" and "*confusing*", to more neutral experiences, such as "*just a bit weird*". Positive aspects included "*inspiring and lovely at times*". The majority articulated that their families were "*trying their best*" or "*a work in progress*" in the face of tough circumstances. With this, many acknowledged their own personal growth and maturity "*the life skills I have developed*" and amongst it all times of joy, "*the silly moments we have, where we can't stop laughing at each other*" and "*the moments at the beach together*" (see Appendix C, page 40).

Findings: A Synthesis Across All Groups

Below, we provide a meta-synthesis of the emergent themes from our field consultations, grouped by five major themes, as articulated by young people, family members and practitioners, with illustrative quotes. Our appendices supply the individual analysis disaggregated for young people (see Appendix C, pages 37 – 40), family members (see Appendix C, pages 41 – 42) and practitioners (see Appendix C, pages 43 – 45). We encourage readers to refer to these.

The Five Major Themes, from Three Perspectives

1. Language/labelling
2. Seeing the invisible experience of young person
3. The wished for nature of support
4. The barriers to support
5. Towards better pathways: What effective referral and support would be

1. Language/Labelling

The young person (*n*=16)
Young people, both connected and unconnected with formal services, expressed a common view that, whilst they undertake caring roles and responsibilities, most do not generally identify as 'carers'. Instead, young people described themselves as *the "responsible one"*, or a *"mediator"* or *"peacekeeper"*. Others recognised themselves as a source of *"strength"*, someone who is *"keeping it together"*, or *"the glue of the family"* (see Figure 2).

The language of "young carer" seems to be policy based and not something that appears in the naturally occurring narrative of the young people or the family members consulted (see Appendix C, page 37).

Family members (*n*=6)
Family members were reluctant to use terms such as 'young carer' and many baulked, understandably, at the term "young person with caring responsibilities."

> *"We don't really use carer... we generally use support person as a term. It feels kinder to us"; "That term is new to me, and I don't use the term, neither do my kids"; "They (young people) don't see themselves as doing anything differently".*

Practitioners (*n*=38)
Practitioners all agreed that young people do not self-identify as a 'carer'. They identify as being a member of a family, where this is normal or business as usual, and therefore as not needing of or eligible for help.

> *"The language we use to describe people, particularly in their relational roles has a powerful effect on them, more so when people are feeling under pressure. It is clear the term 'young carer' doesn't resonate with young people."*

> *"Young people wrap around their family unit and say 'This is my responsibility to care for this person. Well, I've grown up doing this. It's part of how we operate as a family'".*

> *"Many young people struggle with identifying as young carers as they feel it is simply their responsibility as a child or sibling to provide the carer support to their family members. They are hesitant to reach out for support, especially because they do not identify as a young carer."*
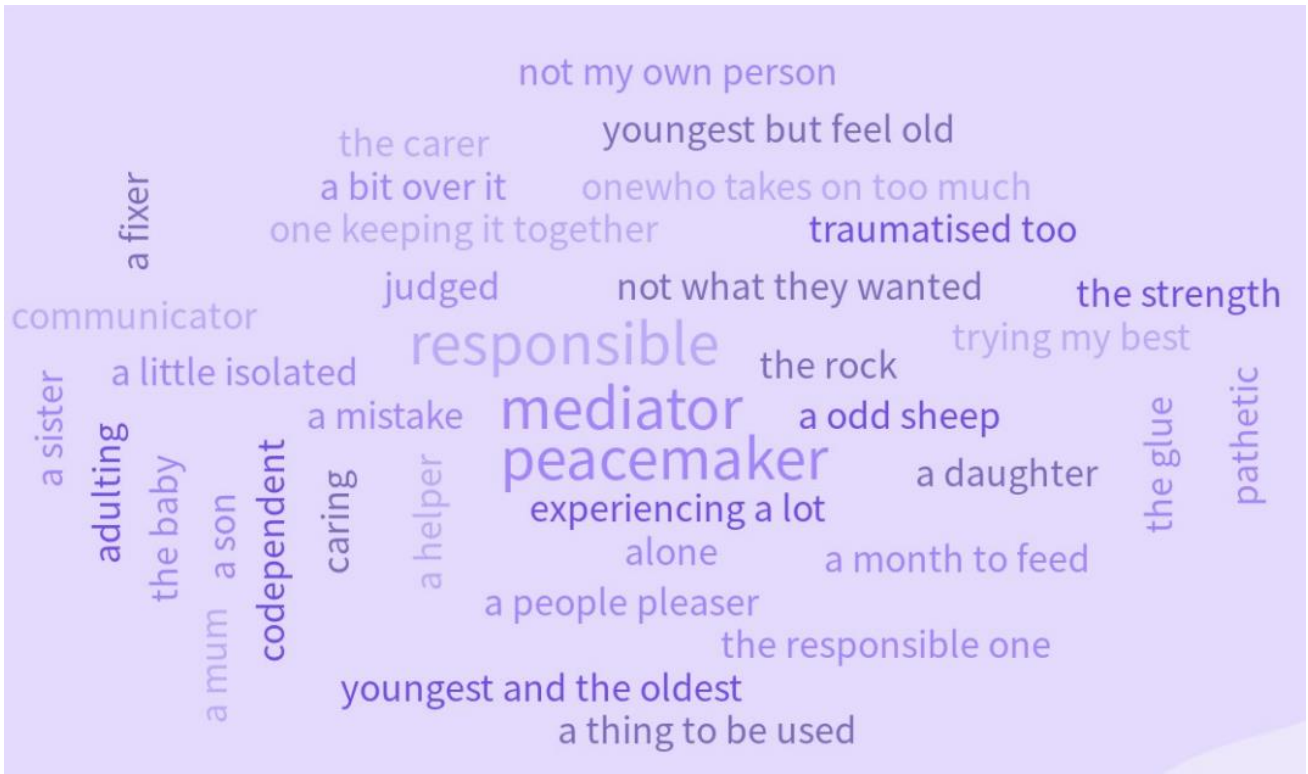
Fig. 2. Young peoples' descriptions of living with caring responsibilities, on Mentimeter

2. Seeing the Invisible Experience of the Young Person

Young person (*n*=16)

Lived experience interviews substantially confirmed the findings of the Royal Commission. Specifically, young people with caring responsibilities are burdened both in the moment and over time, yet unseen or overlooked in adult psychiatric settings as people needing support in their own right and hidden in plain sight within school settings.

"Not being understood and supported by medical personnel",

"Having to struggle alone with their mental illness without support",

"Not knowing if you should ask for help from services",

"Despair after despair; stretching yourself to support everyone but yourself and forgetting, to take care of your own needs".

Family member (*n*=6)

While family members described family life on a spectrum from "creative" to "struggling", most participants expressed positive comments, pride and admiration for the young person caring for them, who contributed deeply to the sense of an ongoing family unit.

All family members also expressed the difficult impacts for their young person, as a result of caring during their mental health struggle, alcohol and other drugs concerns or addiction.

"My daughter is incredible at holding space, she is deeply empathetic, she is also so strong and kind...whilst she has to support me at times, she does such an amazing job managing her own stuff. She is mature, has the most amazing sense of humour. She is learning to develop independence and has discovered she is an incredible cook."

"My son is often having to speak on my behalf, advocate for me in medical settings when I can't speak due to seizures or aphasia. He will at times have to co-regulate when I am overwhelmed in public settings".

"The isolation, all the things she misses out on. Sometimes the embarrassment if I am struggling with overwhelm or speech, the anxiety of my health issues, the confusions of the unpredictability"; "sometimes when I have episodes of fatigue and exhaustion she misses out on a lot of things and has to assist with meals a lot".

"She gets overwhelmed, not feeling safe, withdrawn, having to see me struggle really upsets her"; "Doesn't go out with friends after school or sports things like that".

2. Seeing the Invisible Experience of the Young Person

Practitioners (*n*=38)

Most spoke about young people with caring responsibilities as the *"invisible members of the family"*. Many were keenly aware of the stigma and shame associated with mental illness, and of young 'carer' guilt about looking after themselves.

Practitioners highlighted that young people may view caring responsibilities as a *"normal"* part of *"family life"*.

> *"Young people wrap around as a family unit and say this is my responsibility to care for this person, well, I've grown up doing this. It's part of how we (young people) operate as a family"*

Young people with caring responsibilities often do not see themselves as 'carers'. One of the participants said:

> *"Many young people struggle with identifying as young carers as they feel it is simply their responsibility as a child or sibling to provide the carer supports to their family members. Many young people struggle with their caring responsibilities and are hesitant to reach out for support, especially when they do not identify as a young carer"*

Most practitioners reported that some young people were more likely to remain "hidden" and "invisible" than other young people with caring responsibilities. These include young people affiliating with (but not limited to) culturally and linguistically diverse communities, Aboriginal and/or Torres Strait Islanders, diverse genders and sexualities.

It was reported that there appear to be a stronger expectation of young people engaging in caring responsibilities within families affiliating with Indigenous heritage or other culturally and linguistically diverse groups.

> *"I used to work in refugee and migrant settlement services. Usually, the children, especially the oldest, had to pick up the role of being the carer for their parents regardless of the parent's age or health conditions. Obviously, this is not an informed decision".*

Some practitioners indicated that this would imply that young people and their families are often not aware of their entitlements in terms of support and services.

> *"They (young people) see themselves as I'm a child of a person with a mental illness or with an alcohol and drug issue...they're not going to be aware of what they're entitled to".*

3. The Wished for Nature of Support

Young person (*n*=16)

The young people's responses in this category reflect the flow on effects of parental absence and the wish for a caregiving presence who could be focused on their needs, amidst the urgency of their parent's needs.

What I needed support with:

Themes of self-reliance dominated, lack of awareness that support services existed and confusion about how to access them. The needs expressed were remarkably uniform across cultural backgrounds, and across family circumstances (Appendix C, page 39).

> *"Knowing I'm allowed to exist outside of my family and having a space to do so",*

> *"Figuring out how I want my relationship with my family to be",*

> *"Understanding myself"; "Understanding and knowing how to take care of myself rather than just everyone around me",*

> *"Needing time off school because of my caring roles",*

> *"My parent's intervention order",*

> *"Sexual health stuff",*

> *"Everything, it was hard to even know and find out what types of assistance are available",*

> *"Understanding the diagnosis",*

> *"I was my own greatest source of support".*

The long-term nature of support was a feature for this young person:

> *"I believe that long-term support in the form of checking in is incredibly important for YC. In my own experience, I've found that I experience(d) long term trauma as a result of my time caretaking. It's something that shaped my personality and I am still actively working on unlearning fears and behaviours as a result. It will not be enough to just supply the support".*

Amidst the crush of concern and care, the young people were nearly unanimous in the developmentally appropriate wish for growing autonomy from their parents and family. Some young people spoke to the loss of childhood.

> a *"sense of independence and access to space for myself",*

> *"money to enjoy life"; "financial freedom",*

> *"rest"; "breaks"; "boundaries"; "mental health days"; I deserve "to be a kid".*

Who offered help?

Satellite Foundation, Headspace; Beyond Blue, teachers, school counsellors, general practitioner, counsellors, psychologist, family therapist, youth worker, and online services.

3. The Wished for Nature of Support

Family member (*n=6*)

For most family members, there was more reliance on informal support from the extended family network than on formal support. The absence of formal support was stark.

> *"We need more support for her own mental health. The toll it takes on young people growing up in unpredictable situations, particularly health/mental health based is hard. The isolation is hard so more social support, social groups".*

> *"More ability to have some financial independence and help learning the skills needed. For example, free first aid and mental health first aid training".*

> *"She (the young person) does not have camps or support workers she debriefs with. Her older siblings help when they aren't busy. But I still feel people don't understand how hard it is on her own".*

> *"Our friendship groups mainly through school connections have been amazing support, driving my kids to sport etc. Including them on holidays trips".*

In their own words, family members said:

> *"Random agencies sometimes ask",*

> *"High school does not ask, don't care",*

> *"Agencies take information as a way to opt out sometimes",*

> *"I wish services and supports would understand....they did not see how hard it was for her (the young person)".*

Often extended family members were unable to offer support when this was most needed. Three mentioned helpful support from formal organisations: Little Dreamers, Satellite Foundation and TemCare.

Practitioners (*n=38*)

Participants reported a variety of ways in which young people are referred to support services. Some examples included Helpline via a google search, word of mouth, brochure, GP, a mental health care plan, school, the family member's treating team. Some reported that despite identification, knowledge of referral processes or options was often inadequate.

> *"If the parent's clinician is tuned in enough, they will identify the young person and their needs...but often they are not aware where to refer them."*

4. Barriers to Support

Young person (*n*=16)

"At school I feel alone; and a little isolated". "I think it would have been helpful for school to be aware of it....if I was running like late for an assignment, I sometimes didn't feel comfortable to say why".

"A wish to be asked "R U OK" by professionals, in a "less scary way...and making me feel reassured by listening to me and saying that how I feel is totally okay and its okay to be sad or whatever".

"Only without calling child protection services, I just want empathy and support – it only makes things more difficult when you do that".

Family member (*n*=6)

Some family members felt that routine identification of young people could be a negative if conducted as a risk-identification exercise, bringing with it unwanted increased scrutiny. This led to significant reluctance to seek help and a preference for a "keep your head down" approach for two families. For others, the wish for the removal of barriers to help was clear.

"Having knowledge on what she can access would help";

"I wish there had been a message that getting help is something that is okay and not a source of shame. We puddled along but it would have been so good for him to be supported - perhaps I would have learned how to better support him".

Both realities - fear and the want of help - are key to shaping effective systems response.

4. Barriers to Support

Practitioners (*n*=38)

Risk Orientation: Services adopting a risk rather than support-oriented identification to engagement with young people.

Out of scope: Service culture, practice frameworks and resourcing are not currently inclusive of routine check-in on the well-being of each family member; minimal resourcing to be responsive when needs are detected beyond immediate care of the affected family member.

No routine information collection about the family's composition, needs and strengths. Most spoke about young people with caring responsibilities as the *"invisible members of the family"*. There were no or minimal structures to support the identification of parents within adult mental health services, let alone structures to identify and engage with the support needs of their children. Wholistic, relational practices were notably absent.

Siloed approaches: No or minimal inter-service or cross-sector coordination, collaboration, and partnerships. Most participants pointed to a system that is not joined up. Adult mental health services, substance and/or addiction services were rarely connected to the young person's school.

Rules and regulations about consent. If a family member is not in a stable mental state, they may not be in a headspace to be able to make decisions / give consent for services to support their young children who may be involved in caring responsibilities.

Young people's lack of self-identification as "carer". Identity of family as normal and not needing or deserving of support.

Stigma and shame associated with mental illness.

Young carer guilt about looking after themselves.

Parents' lack of trust in services, and reluctance to share information (e.g., especially for First Nations families, due to fear of Child Protection involvement). In these regards, the need for these fears to be anticipated and fully seen was emphasised, alongside 'normalising' talks about cross cultural family struggles with mental illness, substance use or addiction.

Lack of information about entitlements, available services and how to navigate through services.

Pragmatics: time and transport

Parental consent: difficulties gaining parental consent for the provision of support to children under 16 was again nominated as a key barrier.

5. Toward better pathways

Young person (*n*=16)

> *"Support looks like someone who listens to me and tries to help when I need it"*

> *"A less scary way to find help...by making it easier to go through the processes.... I get confused".*

Who I would like help from (in order of importance to the young person)
- **Family members:** most wished for more open communication and support within the family unit
- **Friends:** only half reported that a friend knew about their circumstance. A wish for friends in similar circumstances
- **School and teachers:** wish for their awareness for personal support, advocacy and special consideration
- **Healthcare professionals:** involvement with caring responsibilities was often not recognised
- **Legal, court and Child Protection professionals:** appear as threats rather than supports in the mix for young people

In their own words, young people stated that:

> *"If only they could understand me and my challenges at home",*

> *"I wish my friends knew how hard it was to juggle home life and my own mental health",*

> *"A wish for teachers who listen to me and comfort me",*

> *"Yes, I would want help but only without calling Child Protection services, I just want empathy and support – it only makes things more difficult when you do that".*

Family member (*n*=6)

Family members emphasised the need for adequate information and knowledge about services, together with destigmatising messages about accessing them. Some family members highlighted the need for mental health and wellbeing related services for their young person and others nominated the need for financial support.

Participants collectively identified a wish for clear options of support to consider, introduced in a destigmatising manner with a transparent intent to help and not to scrutinise the young person or their families.

5. Toward better pathways

Practitioners (*n*=38)

"...we need to break down some of those barriers for "young carers" (young people with caring responsibilities) so that they can connect with other young carers from a whole range of different support services and break down the barriers of understanding and support that young carers receive in environments like school settings, university settings, workplaces, normalising the need for flexibility, compassion and understanding across these sectors".

From a service and system perspective, strong inter-service coordination, collaboration, and partnerships in meeting the specific needs of young people with caring responsibilities were called for.

A risk-oriented identification of young people leads to greater focus *"in a negative sense"* compared to *"provision of actual support"*, and *"enabling well-being"*. In this light, one family practitioner working in adult mental health offered these steps:

1. "Always ask the question of the person being cared for, about the situation of their carers in their family,

2. Provide psychoeducation to the person being cared for (the patient/client) about the importance of their children and young people being supported in their caring role

3. Gain parental consent to engage and work with their children and young people

4. Approach the young person and provide support

5. Adopt a relational practice - a whole family approach, also to the benefit of supporting the patient's recovery".

In terms of strengthening referral pathways, most participants spoke about *"purposeful referrals"* and *"starting with the family"*. For example, one of the FaPMI Community Worker for Children and Young People stated that:

"Starting where the family is at...the young child, the young person, and their families may already have formal and informal sort of networks that can be extended or built on, rather than the idea of, you know, sending them off to another thousands of referrals that actually might make their life much more complicated and might not actually relieve or provide any support".

In line with this "purposeful referral", some of the participants emphasised the need to shift away from "clinical" perspectives to "opportunity" perspective, when engaging with young people with caring responsibilities. For example, one of the participants (FaPMI coordinators) stated that:

"It's more about the opportunities for this young person, what this family needs to have happy, healthy relationships and develop and grow and have positive futures... the opportunities that parents might like for their children and young people".

In terms of type of services, the professionals and practitioners mentioned a great deal of variation in support and services for young people and their families.

Examples of support include:

- Individual work and/or group activities with the young person (e.g., recreational, and fun activities)
- Respite care
- Work with the whole family
- Practical and financial support (e.g., brokerage funds)
- Mental health and social support
- Support with engagement in school and education
- Support with employment.

Collectively the participants emphasised the need for a dual focus on individual provision of tailored support to the young person and support within a family context: *"Family therapy services can offer whole of family mental health support"* (see Appendix C, page 45).

Summary and Combined Recommendations from the Rapid Review and Field Studies

The aim of this two-part collaborative project was to synthesise current evidence and generate new knowledge to inform policy initiatives and practice reform, to strengthen identification of young people with caring responsibilities, and their engagement, through effective referral pathways in tailored support services. The review of existing literature provided a clear view of the gaps in our knowledge base. The latter provided insights into the lived and living experience of caring responsibilities from three perspectives: the young person, the family member and the practitioner.

Recommendations for Strengthening Current Approaches and Practices

1. **Language**
   A. The language of 'carer' does not resonate with young people and its use should not be continued. Identify a young person as primarily a 'family member' and a 'supporter'.
   B. Use the normalising language of social and emotional well-being, as opposed to mental illness language, to move the focus from a risk and deficit to support.

2. **Service identification of family status and context**
   A. Develop clear policies that address the invisibility of young people affected by mental ill-health in the family, ensuring primary systems consistently enquire into parenting and familial status, and adopt a relationally informed approach to adult mental health care.
   B. Create practice guidelines that:
      a. are informed by young people with lived experience in a support role
      b. make clear expectations for all mental health professionals to enquire about the presence and well-being of any young people connected to the affected person
      c. consistently enquire about and record parental status during intake and entry to care
      d. compensate for known bias in recognising a parent's status, especially for men and parents in LGBTIQ families, and
      e. link to clear record keeping, follow-up processes for screening the well-being of young people once parental status is identified, procedures for referral and support, and review.

3. **A strengths-based, relational focus through capability uplift**
   A. Post identification of the young person, in primary health and tertiary mental health and AoD settings:
      a. Incorporate multidisciplinary training of staff to focus on whole-of-family engagement
      b. Align expansion and ongoing support of workforce capability in family-inclusive practices
      c. Pilot implementation of the strengths-based workforce training such as *Single Session Family Consultation* (Bouverie Centre), as a tailored early supportive conversation, to elicit needs and co-design supports
      d. Develop knowledge and skills in approaches to assessment with the young person to understand their needs, within their family, educational and developmental context – neither assuming the young person's resilience nor assuming need.
      e. Develop community health-based programs of ongoing support for the young person in their local networks. This is particularly relevant for First Nations and CALD communities.
   B. Frameworks that are not time limited, that provide follow-up and individualised check-ins are essential. The onus for this should lie with the service system.

4. **Research and evaluation**
   A. Provide support for research in the Victorian context to understand further how we better identify and engage young people and support best outcomes for young people across a diversity of context.
   B. Create more opportunity for lived experience researchers through mentoring opportunities as a pathway for gaining experience and providing meaningful and much needed input.

5. **Awareness raising**
   A. Increase awareness for professionals in all sectors about stigma associated with mental health and AoD conditions, and monitor outcomes of this for support seeking and well-being in young people.
   B. With substantive lived experience input, develop and pilot a schools-based trial for normalising family challenges of physical and mental health burdens, following on the success of aligned programs such as the Jigsaw program, for creating safe space to talk about family violence.
   C. Develop public health awareness-raising strategies normalising the experiences of young people in support roles.

6. **Referral and access to support and services**
   A. Create clinical guidelines to enable 'purposeful referrals' that address the needs of the whole family. In this, ensure a 'referring on' mentality is not created.
   B. Resource the development of a clear network map or repository of available services for young people, defined as opportunities, rather than support services.
   C. Develop strong inter-service coordination, collaboration, and partnerships in meeting the specific needs of young people. Establish a cross sector network to plan collaborative pathways to identify mechanisms for information sharing, identifying and supporting affected young people. Ensure membership is inclusive of LLE young people, mental health, family and carer led services, trauma, drug and alcohol, advocacy and education sectors.
   D. Pay particular attention to recognising children of family members who are not themselves engaged in formal psychiatric or AoD support services.

Expected Outcomes

The key expected outcomes for young people, families, services, and systems are described below:

Young People and Families
- Young people in support roles are identified, acknowledged, and their lived experiences are validated and respected.   - The age of a young person is taken into account at all points in the engagement journey and offered age-appropriate supports and information.   - Young people and their families are able to easily find and independently access information and services.   - Young people are included in family sensitive practices in adult services, with a focus on understanding their well-being and safety, the nature of their support role, its meanings to the young person in context, and their short and longer term needs in light of this   - Young people are facilitated in their support role and responsibilities, with their own mental health and development.   - Young people with support responsibilities are given effective advocacy for their needs with education and employment settings, increasing the likelihood of completing school and transitioning to further education or employment.   - Improved family relational health and wellbeing, documented through prospective research strategies.

Services and Systems
➢ Young people and their families are routinely included in co-design initiatives, service improvement and program design.   ➢ Standardised data is collected about the familial status of individuals who access mental health, alcohol, and other drugs services.   ➢ Enhanced documentation and referral processes are implemented across adult services that in turn better supports earlier identification, needs assessment and engagement with support services.   ➢ Cross sector workforce training and implementation strategies that support best practice for young people and their families, across primary and tertiary care systems community and educational settings, are utilised.   ➢ A service system with capacity and willingness to take a normalising whole-of-family approach to reduce stigma and supporting young people whose lives are affected by the mental ill health of a family member is provided.   ➢ A multi-systems approach is applied, with enhanced partnerships and collaborations across services and sectors, that reflects and increases responsiveness to the diversity of young people and their family contexts.   ➢ Effective referral pathways are provided.   ➢ Continuous service improvement is implemented through co-designed, meaningful local research that evaluates new initiatives and contributes new knowledge to this new and rapidly evolving area of enquiry.

The findings of this two-part study provide key evidence to inform future policies and services to strengthen identification, engagement, referral, and access to support services that meet the needs of young people and their families. Again, we remind the reader that the study details are elaborated in the extensive appendices attached to this summary report. Further details on design and methodology are available on request from the Bouverie Centre's research team.

This work was achieved through a strong, authentic collaboration of service providers, stakeholders, young people and their family members, and a multi-skilled research team. We trust these findings and their aligned recommendations provide a solid foundation for next generation policy settings and practice guidelines.

Project Team

The Bouverie Centre of La Trobe University

Mohajer Hameed (Senior Research Fellow)

Jessica Opie (Lived-Experience Consumer Academic Researcher)

Jennifer McIntosh (Professor of Systemic Practice and Family Therapy)

An Vuong (Research Assistant)

Sonia Marchionda (Research Project Officer)

Lara Wallis (Carer Lived and Living Experience Researcher)

Hanan Khalil (Associate Professor and Carer Academic)

Felicity Painter (Research Officer)

Hanna Jewell (Coordinator of The Victorian FaPMI Program)

Jane Schinas (FaPMI Statewide Project Officer)

Natalie Pearce (Research Librarian)

Sandra Kuntsche (Associate Professor)

The Satellite Foundation

Rose Cuff (CEO and co-founder)

Mia Boonen (Youth and Consultation Coordinator)

Leanne Vuong (Training & Education Resources Officer)

Peer Researcher

Scarlett Davidson (young person with lived and living experience of caring responsibilities)

Department of Health

Bec Martindale (Senior Policy Advisor, Lived Experience Branch, Mental Health and Wellbeing Division)

Daniel Gor (Senior Lived Experience Advisor – Family/Carer, Lived Experience Branch, Mental Health and Wellbeing Division)

Safer Care Victoria

Tamara Layley (Lived Experience Adviser – Carer)

References

Aromataris, E., & Munn, Z. (2020). JBI Manual for Evidence Synthesis. In E. Aromataris & Z. Munn (Eds.). https://doi.org/10.46658/JBIMES-20-01

Balducci, C., Mnich, E., McKee, K. J., Lamura, G., Beckmann, A., Krevers, B., Wojszel, Z. B., Nolan, M., Prouskas, C., Bień, B., & Öberg, B. (2008). Negative impact and positive value in caregiving: Validation of the COPE Index in a six-country sample of carers. *The Gerontologist*, *48*(3), 276-286. https://doi.org/10.1093/geront/48.3.276

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

Chevrier, B., Lamore, K., Untas, A., & Dorard, G. (2022). Young adult carers' identification, characteristics, and support: A systematic review. *Frontiers in Psychology*, *13*. https://doi.org/10.3389/fpsyg.2022.990257

Dawson L, River J, McCloughen A, Buus N. 'Should it fit? Yes. Does it fit? No': Exploring the organisational processes of introducing a recovery-oriented approach to mental health in Australian private health care. Health. 2021;25(3):376-394. doi:10.1177/1363459319889107

Fargas-Malet, M., & McSherry, D. (2018). The mental health and help-seeking behaviour of children and young people in care in Northern Ireland: making services accessible and engaging. *The British Journal of Social Work*, *48*(3), 578-595. https://doi.org/10.1093/bjsw/bcx062

Lutz, W., & Hill, C. E. (2009). Quantitative and qualitative methods for psychotherapy research: Introduction to special section. *Psychotherapy Research*, *19*(4-5), 369-373.

McDougall, E., O'Connor, M., & Howell, J. (2018). "Something that happens at home and stays at home": An exploration of the lived experience of young carers in Western Australia. *Health & Social Care in the Community*, *26*(4), 572-580. https://doi.org/10.1111/hsc.12547

McKee, K. J., Philp, I., Lamura, G., Prouskas, C., Oberg, B., Krevers, B., Spazzafumo, L., Bień, B., Parker, C., Nolan, M. R., & Szczerbinska, K. (2003). The COPE index--a first stage assessment of negative impact, positive value and quality of support of caregiving in informal carers of older people. *Aging Ment Health*, *7*(1), 39-52. https://doi.org/10.1080/1360786021000006956

Reupert, A., Bartholomew, C., Cuff, R., Foster, K., Matar, J., Maybery, D. J., & Pettenuzzo, L. (2019). An online intervention to promote mental health and wellbeing for young adults whose parents have mental illness and/or substance use problems: theoretical basis and intervention description. *Frontiers in psychiatry*, *10*, 59.

Reupert, A., Maybery, D., Bartholomew, C., Cuff, R., Foster, K., Matar, J., & Pettenuzzo, L. (2020). The acceptability and effectiveness of an online intervention for youth with parents with a mental illness and/or substance use issue. *Journal of Adolescent Health*, *66*(5), 551-558.

Reupert, A. E., Cuff, R., Drost, L., Foster, K., Van Doesum, K. T., & Van Santvoort, F. (2013). Intervention programs for children whose parents have a mental illness: a review. *Medical Journal of Australia*, *199*(3), S18-S22. https://doi.org/10.5694/mja11.11145

von Doussa, H., Hegarty, M., Sanders, B., Cuff, R., Tivendale, K., McLean, S. A., & Goodyear, M. (2023). Peer support for children of parents with mental illness (COPMI) in Australia: responses from children, parents and facilitators of the CHAMPS peer support program. *Advances in Mental Health*, *21*(1), 55-66. https://doi.org/10.1080/18387357.2022.2075411

Whitley, J., & Wooldridge, R. (2018). *Sheffield Young Carers - Family Project evaluation*.