ARAFMI
you are not alone

National Carer Strategy

Consultation Submission

13 September 2024

About Arafmi

Arafmi, founded in Brisbane in 1976, is a not-for-profit organisation supporting people living with mental ill-health, their carers and families. As the peak body for unpaid mental health carers in Queensland, Arafmi has broad and direct engagement with carers across the state and plays an active role in identifying carers' needs and providing systemic advocacy across all government levels.

Arafmi offers a diverse range of supports and services to mental health carers, including:

- **Systems Advocacy:** Representing the experiences and needs of mental health carers with government, healthcare professionals, and the community.
- **Emotional, Therapeutic, and Practical Support:** Providing direct assistance to those living with mental ill-health.
- **Strengths-Based Support**: Providing targeted assistance to carers, families, and friends, including 1-1 support, support groups, carer respite, and a 24-hour Carer Helpline.
- **Information and Learning Opportunities:** Developing resources and delivering information and capability building sessions to educate carers on self-care and the complexities of caregiving.
- **Community Awareness:** Implementing and partnering in initiatives to reduce the stigma associated with mental health concerns.

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Arafmi acknowledges Aboriginal and/or Torres Strait Islander peoples as the First Nations peoples of Australia and recognises their continuing connection to country, waters, kin and communities. We pay our respect to Elders past, present and future and are committed to ensuring that Aboriginal and/or Torres Strait Islander peoples' voices are heard and respected across Queensland.

1. Executive Summary

As the peak body for unpaid mental health carers in Queensland, Arafmi is eager to ensure the new National Carer Strategy reflects the challenges and needs of those who care for someone experiencing mental ill-health, as they differ in many significant ways from other groups of carers.

Our recent statewide consultations have identified key challenges for mental health carers as – the financial impacts of caring; impacts on carers' mental, emotional and physical health and wellbeing; system navigation and advocacy; and stigma and social isolation.

Carers also told us that the biggest difference to their roles as carers would come from – personal and practical support; financial assistance; information, education and training; improvements to the mental health system; recognition by the mental health system and wider community; and greater support for balancing work and caregiving responsibilities.

We recommend that the National Carer Strategy should:

1. Give specific consideration to the additional challenges and needs of mental health carers and include tailored approaches to addressing these.
2. Recognise and support the needs of a diverse range of carers and ways of caring, take a rights-based and whole-of-government approach to addressing the needs of carers, and require the review of carer legislation and associated legislation to create legally enforceable rights for carers and obligatory duties for public entities and services.
3. Enable information and access to carer supports to be proactively made available at the times and places where carers are most likely to discover a need for them.
4. Provide for a range of accessible respite options for carers and families.
5. Address the right to economic participation for carers, as well as implement measures to address the financial inequality experienced by carers who are unable to work, and which compound over a lifetime of caring.
6. Include strategies for meeting the specific needs of particular groups of carers, including a national research and data gathering component to ensure these specific needs are understood, addressed and appropriately reflected in legislation and policy.
7. Require a review of the adequacy and fairness of carer support payments, as well as consideration of the addition of superannuation to carer support payments.

2. Introduction

Arafmi welcomes this opportunity to provide input to the development of a new National Carer Strategy to support the wellbeing, education, health (including mental health) and safety of Australia's unpaid carers over the next five years.

As the peak body for unpaid mental health carers in Queensland, we are eager to ensure the strategy reflects the challenges and needs of those who care for someone experiencing mental ill-health, as they differ in many significant ways from other groups of carers.

Our submission is informed by our ongoing consultation and relationships with mental health carers, our recent statewide consultation findings[1] and the findings of other recent research and inquiries or reviews into mental health families and carers.

Our policy and advocacy team, which has prepared this submission, is also comprised entirely of staff members with lived experience as mental health carers.

Quotes from mental health carers who have participated in consultations and surveys over the past year are included throughout the submission. We thank these carers for their generosity in sharing their insights and experiences.

3. About Mental Health Carers

The current national Carer Recognition Act 2010 defines a carer as someone who provides personal care, support and assistance to another individual who needs it because that other individual has a disability, a medical condition (including a terminal or chronic illness), a mental illness, or is frail and aged.

Arafmi defines a **mental health carer** as someone who provides unpaid care and support to a person experiencing mental ill-health. They may be caring for a child, parent, partner or other family member, or for a friend or member of their community.

Whilst mental health carers share many of the same challenges as other groups of carers, such as social isolation and financial disadvantage, there are also significant differences in the experiences of carers who support someone experiencing mental ill-health.

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[1] Arafmi (2024). *At what cost: The experiences of unpaid mental health carers in Queensland 2023 – 2024.* Available at A04-Arafmi-Consultation-Report_250624.pdf

The Productivity Commission has previously noted differences in the role played by mental health carers due to:

- the episodic nature of mental ill-health
- relationship strain that can result from mental ill-health
- the fact that mental ill-health typically manifests earlier than many physical health conditions
- the stigma associated with mental health concerns[2].

The episodic nature of mental ill-health is particularly significant from a carer policy, strategy and support service perspective, as it means that mental health carers' roles and responsibilities are frequently unpredictable in terms of intensity and duration.

The impact of the episodic nature of mental ill-health on carers' ability to maintain employment, in combination with the earlier onset of mental ill-health when compared to many other physical health conditions, also exacerbates the financial impacts of caring.

Research commissioned by Carers Australia and published in 2022 found that "At the mean, and at current subsidy settings, Australian carers will lose:

- $392,500 in lifetime earnings to age 67; and
- $175,000 in superannuation at age 67.

Some who are carers for extended periods of time will lose substantially more, with the most affected 10 per cent losing at least $940,000 in lifetime income, and $444,500 in retirement savings."[3]

Due to the nature of mental ill-health and the stigma associated with it, mental health carers are often invisible. In fact, many people caring for and supporting someone experiencing mental ill-health (including children and young people) do not recognise that they are carers and are therefore not captured in existing data sets, nor supported through available carer support services.

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[2] Productivity Commission (2020). *Mental Health Inquiry Report (No. 95).* Commonwealth of Australia.

[3] Evaluate (2022) *Caring Costs Us: The economic impact on lifetime income and retirement savings of informal carers*. Commissioned by Carers Australia

In addition, the recently released *Analysis of unmet need for psychosocial supports outside of the National Disability Insurance Scheme – Final Report*[4], showed that in 2022-23, of the 647,300 Australians aged 12-64 years with a severe or moderate mental illness, 76 per cent were not receiving the psychosocial support that they need. All too often it is mental health carers who are left to bear the responsibilities associated with this massive unmet need.

From a human rights perspective, family, kin and other supporters should have the right to choose the extent to which they provide unpaid care for someone who is experiencing mental ill-health, and the extent to which they access external supports and services to provide this care. Due to a lack of access to mental health services and a range of other factors, family, kin and other supporters can feel they have no alternative, or worse, feel co-opted or pressured into assuming a carer role – often to the detriment of their own health and wellbeing, their personal and family relationships and their financial wellbeing.

> ***"I'm at breaking point trying to keep everyone afloat. But we [carers] don't have the option to break, otherwise who will support our loved ones?"***
> ***(Statewide consultation participant)***

For some carers, the mental health condition of the person they care for can result in risk to the carer's safety. Sometimes mental health conditions also underpin situations of domestic and family violence and coercive control. In such situations, mental health carers can be forced to choose between the safety and security of themselves and their family, and the human rights and dignity of the person they care for. It can be an extremely confronting and stressful experience for a carer to have to call for help, knowing that the only option available will result in the deprivation of liberty of a person they love and care for.

This combination of particular circumstances evidences a need for specific consideration of the needs of mental health carers in the development of the National Carer Strategy.

Recommendation 1.
The National Carer Strategy should give specific consideration and recognition of the particular circumstances, challenges and needs of those who care for someone experiencing mental ill-health and include tailored approaches to addressing these.

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[4] Report available at https://www.health.gov.au/resources/publications/analysis-of-unmet-need-for-psychosocial-supports-outside-of-the-national-disability-insurance-scheme-final-report?language=en

4. Response to the National Carer Strategy Discussion Paper

The feedback below reflects Arami's understanding of the experiences and needs of mental health carers in relation to key topics from the National Carer Strategy Discussion Paper.

Principles of the Strategy

Arafmi believes that the Strategy should be underpinned by:

- Recognition of the diversity of carers and caring roles, and the specific needs and challenges of particular groups of carers, including mental health carers, young carers, male carers, and carers in First Nations, LGBTQIA+, Culturally and Linguistically Diverse and rural and remote communities.

- Recognition of the rights of carers, including a rights-based approach to the review and reform of national and jurisdictional carer legislation. Consideration should be given to the rights of carers within government-funded systems and services, as well as the rights of carers as citizens, including the right to social and economic participation. The mental health Family and Carer Research and Advocacy Network and Mental Health Australia have just released *A joint statement of rights for Australian families, carers and supporters in mental health*, which outlines what these rights look like for mental health carers[5].

- A whole-of-government approach to addressing the needs of carers, including consideration of the roles of national and state/territory government departments and agencies across areas such as health (including mental health), education, disability, housing, child protection, aged care and justice.

- A review of carer legislation across national and state/territory levels to ensure consistency across jurisdictions, and to create legally enforceable rights for carers and obligatory duties for public entities and services.

- Reflection of carer legislation in NDIS, disability, mental health and aged care legislation and policy.

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[5] The joint statement can be accessed at https://tandemcarers.org.au/common/Uploaded%20files/Public%20Documents/Research/20240902%20Joint%20statement%20of%20rights.pdf

- An approach to carer recognition and support that spans a potential lifetime of caring and offers differentiated solutions for key points in the caring journey.
- Recognition of the notable impacts of caring beyond just primary carers, to include considerations of the support needs of families (including 'families of choice') and kin.

Recommendation 2.

The National Carer Strategy should recognise and support the needs of a diverse range of carers and ways of caring, take a rights-based and whole-of-government approach to addressing the needs of carers, and require the review of carer legislation and associated legislation to create legally enforceable rights for carers and obligatory duties for public entities and services.

What does the mental health caring role look like?

Across more than 500 contributions to Arafmi's recent statewide consultations, the most commonly mentioned roles played by mental health carers were:

- **Provide emotional support**: Mental health carers provide emotional support, understanding, and comfort to the person they care for.
- **Provide practical assistance**: Mental health carers often engage in practical tasks such as organising appointments and supporting the person they care for to attend them, managing medications, providing transport, assisting with decision-making and planning, and assisting with daily activities like cooking, cleaning, and personal care.
- **Advocate for the person they care for and navigate systems**: Mental health carers frequently act as advocates, navigating complex systems such as healthcare, social services, and support networks. This involves coordinating with healthcare professionals, accessing resources, and advocating for the needs of the individual they care for.
- **Build knowledge and combat stigma**: Mental health carers often need to educate themselves about mental ill-health to understand the specific challenges faced by the person they care for, as well as to promote awareness and acceptance of mental ill-health within their communities.

- **Make personal sacrifices**: Many mental health carers spoke about the personal sacrifices they make, including putting their own needs behind those of the person they care for. They also spoke of the demands of coping with the stress and emotional toll that arises from supporting someone with mental ill-health.
- **Constantly monitor, supervise and manage crises**: Caring for someone experiencing mental ill-health often requires constant vigilance and monitoring of their well-being. This includes observing changes in behaviour, mood and symptoms, as well as providing crisis intervention when necessary.
- **Provide financial support**: This includes supporting the payment of medical expenses, living expenses and other financial commitments.
- **Encourage professional help and social connections**: Mental health carers often play a crucial role in encouraging individuals experiencing mental health issues to seek professional help, whether that be therapy, counselling, or medical treatment. They are often also a facilitator of social interactions for the person they care for to help combat social isolation.
- **Create a stable environment**: Providing a stable and supportive environment was highlighted by many carers as an essential component of caring for someone experiencing mental ill-health. This includes minimising stressors, establishing routines, and ensuring the safety of the person they care for.[6]

Support for mental health carers

Awareness

It is apparent from our work with mental health carers that not only do many people who provide unpaid care and support to someone experiencing mental ill-health not recognise they are carers, but that even those who do identify as carers are often unaware that support is available for them.

An additional challenge is that for many reasons (including stigma, cultural obligations and expectations, fear of child safety implications and concerns about the privacy and dignity of the person they care for), carers can be reluctant to ask for help even when they know it is available.

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[6] Arafmi (2024). *At what cost: The experiences of unpaid mental health carers in Queensland 2023 – 2024.* p10-11 Available at A04-Arafmi-Consultation-Report_250624.pdf

“I know I can get the support but find it hard. I’ve never had to ask for help before but now I need all the help I can get but I’m struggling to ask for it.” (Statewide consultation participant)

“I am only now just realising there are supports out there for us. I'm yet to push my shame aside as I feel like getting supports mean I am failing but I hope to soon have the strength to reach out for some supports.” (Statewide consultation participant)

The carer survey conducted as part of Arafmi’s statewide consultations showed that no more than 25 per cent of respondents accessed any type of carer support, such as navigation services, support groups, counselling or respite.[7]

This points towards a need for the National Carer Strategy to raise awareness of carers and the services and supports available to them. It also points towards a need to better understand the barriers that prevent carers accessing available supports and to put strategies in place to address these.

Types of support

Our statewide consultations and annual Carer Survey have highlighted a range of areas in which mental health carers are seeking additional support, including:

- support for emotional wellbeing and self-care
- practical assistance with daily tasks and caring responsibilities
- access to professional support for physical and mental health
- access to respite services, particularly in times of crisis
- support for the whole family, not just the primary care giver(s)
- mental health literacy
- skills to advocate for the person they care for.

The consultation findings also highlighted the need for mental health carer support services to be tailored for, and made available at, different points in the ‘carer journey’. For example, the beginning of the carer journey is often a very challenging time for mental health carers, characterised by high levels of emotional stress and a need for easy-to-understand information and assistance to navigate service and support systems. Throughout the mental

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[7] Arafmi (2024). *At what cost: The experiences of unpaid mental health carers in Queensland 2023 – 2024.* p23

health carer journey, periods of crisis need supports such as respite, and periods between crises can provide moments for carers to address their own mental and emotional wellbeing. Mental health carers who have been caring for 10 and 20+ years can be experiencing emotional and physical burn-out and are often looking for assistance to plan for what happens when they can no longer care.

"You often find out the hard way what's available and what would've helped in the early stages. It would be good to have someone support you from the beginning and throughout the journey to help connect to services."
(Statewide consultation participant)

"[We needed] someone to navigate all the services and help with knowing what needed to happen next. We never knew who to listen to."
(Statewide consultation participant)

"In the past I've had a breakdown due to the pressures. I was in hospital for five months due to doing it alone."
(Statewide consultation participant)

Research being conducted by Dr Marianne Wyder[8], which is mapping the carer journey and support needs against the recovery journey of people experiencing mental ill-health, may offer further ideas and insights into the ways in which mental health carer supports might be conceptualised within the National Carer Strategy.

Access to support

Feedback from our Carer Support Services team and our 2024 Carer Survey has indicated that existing services and supports for carers can be difficult to access due to service hours not matching with carers' availability and inability to access in-person supports due to caring responsibilities, as well as the complexity of registering for services and traumatic intake processes. Carers responding to our 2024 Carer Survey shared some of their challenges in trying to access support services beyond those offered by Arafmi.

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[8] Senior Research Fellow, Research and Learning Network, Metro South Addiction and Mental Health services

Reported barriers included:

“Confusion about what the services are, confusions about the pathways to access services, confusions about long wait lists and what actually is available that's helpful rather than dictated support assumptions about what you need.” (Annual survey respondent)

“Not hearing about what is being offered to carers unless you are in the know.” (Annual survey respondent)

“Invasive registration process/questions” (Annual survey respondent)

“Too hard; long wait” (Annual survey respondent)

The times at which mental health carers are most often in need of support are also often times of great emotional distress and overwhelm. In these periods, carers do not have the time or headspace to be able to search for support or to navigate complex processes to access them. Arafmi suggests that carer supports should be automatically triggered and made available at key points in the caring journey. For example:

- When someone experiencing mental ill-health is first admitted to hospital or specialist mental health facilities, carers should be provided with easy-to-understand information about support services and/or be contacted by a carer peer worker or other support person.
- GPs are often the first point of contact for carers when things are not going well. GPs could be given the authority to develop a Carer Plan that enables subsidised access to a range of support services, in the same way that a Mental Health Plan or Chronic Disease Management Plan enables someone to access psychologist and allied health supports.
- Emergency respite should be made readily available for moments of crisis.
- Free or affordable services should be available to help carers plan for what happens when they can no longer provide unpaid care for the person they support.

Recommendation 3.
The National Carer Strategy should enable information and access to carer supports to be proactively made available at the times and places where carers are most likely to discover a need for them.

Respite

One of the common themes arising out of our statewide consultations was the difficulties mental health carers have in getting a break from their caring responsibilities, leading to burn-out. Carers have reported that most of the stated-funded respite services that existed prior to the introduction of the NDIS have disappeared, leaving carers very few options, particularly in times of crisis and emergency.

Arafmi provides day and overnight respite options for carers which has provided considerable insights into mental health carers' experiences and needs, such as:

- Mental health carers often go for extended periods, sometimes more than 20 years, without breaks from caring, which leads to burnout, family breakdowns and the development of mental ill-health themselves.
- Planning to have a break, even for a day, is often complicated, requiring considerable forward planning to ensure they have arrangements in place for the person they care for to be adequately supported.
- Access to free day or overnight respite is essential. Many carers are not in a position to be able to pay for respite accommodation, transport costs and support, but desperately need a break to prevent and minimise the short- and long-term impacts of caring on their emotional and physical wellbeing.
- Intake processes for respite need to be personalised and easy to access so carers are not faced with additional barriers. This includes the ability to access planned and emergency respite easily.
- Having options of types of respite for carers is important. This includes:
    - day respite, as carers often can't take more than a day away from their situation or don't feel confident doing this
    - overnight respite close to where they live, so it is easily accessible
    - overnight respite further away, so they are in a fresh environment away for others in their local community where there could be stigma
    - respite on their own with access to supports and wellbeing activities tailored to their own needs and goals
    - respite with other carers to build connections and capacity

    - respite with other family members to have much needed time to nurture these relationships, which are often neglected due to competing demands. It is particularly important for other siblings to have time with their parents.

Feedback from the more than 100 mental health carers who have stayed at Arafmi's Respite Hub since it opened in November 2023 also demonstrates the impact respite has for carers. For example:

"The respite has made such a difference to my outlook. I can now see a positive future ahead. I am able to think much clearer and have come home happier and less stressed." (Respite recipient)

"After caring for 54 years, my heart is full of gratitude that from the time I left home and arrived here … it brought tears to my eyes… that finally this dream was 'ALL ABOUT ME.' Everything was shouting loudly… 'You are a carer; we love and support you!!! We understand & you matter!" (Respite recipient)

"This place is truly exceptional … I had the most peaceful, relaxing and rejuvenating time and appreciated all the thoughtful, kind and loving touches – I almost burst into tears when I saw the beautiful room and treats in a basket for me. Thank you so much for looking after the carers. I've never felt so seen and heard." (Respite recipient)

"This respite has been just what the doctor ordered – a place to rest, recharge and heal. Many thanks for the incredible work you do and here's to many more stays for carers who need time out." (Respite recipient)

Recommendation 4.
The National Carer Strategy should provide for a range of accessible respite options for carers and families that incorporate carer preferences and needs.

Employment and education

As highlighted earlier in this submission, the impact of caring responsibilities on carers' ability to access and maintain employment creates significant financial disadvantage for carers. This is a particular issue for mental health carers who have been caring for decades, as well as for young carers whose caring responsibilities can result in them being locked out of education and economic participation for significant periods of their lives.

In our submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs Inquiry into unpaid carers (2023-24), Arafmi put forward the following work-related recommendations to be considered by the Australian Government in making changes to the Carer Recognition Act 2010:

- **Establish Supportive Workplace Policies**: Encourage employers to create supportive work environments that understand the unique needs of mental health carers. This includes flexible work arrangements and adequate paid and unpaid extended leave provisions for carers.
- **Provide Government Support for Transitions**: Implement government payments and infrastructure, such as aged, disability, and child care, that facilitate mental health carers' transitions into and out of the workforce.
- **Develop Flexible Workplace Practices for Young Carers**: Promote flexibility in workplace scheduling, allowing young carers to balance their responsibilities without the fear of stigma or missed opportunities.
- **Create Awareness and Support Programs**: Implement programs that educate employers about the unique skills and challenges of young carers, fostering an environment that acknowledges and supports their dual role as caregivers and employees.
- **Reform Superannuation to Recognise Gender Differences in Caregiving**: Implement superannuation reforms, including Superannuation Guarantee Contributions on the Carer Payment, to alleviate the gendered financial impact of caregiving, especially for women.
- **Introduce Tax Incentives for Unpaid Carers**: Develop a tax incentive akin to Canada's Caregiver Credit to financially support those consistently providing care to family members, recognising the predominantly female nature of this role.

- **Create a Comprehensive Social Contract Around Work and Care**: Enact policies that reflect a modern understanding of work and care, including provisions for paid leave, flexible job opportunities, prevention of retirement poverty, and gender equality in caregiving roles.

Recommendation 5.
The National Carer Strategy should address the right to economic participation for carers, as well as implement measures to address the financial inequality experienced by carers who are unable to work, and which compound over a lifetime of caring.

Priorities

Across the recent statewide consultations conducted by Arafmi[9], the following were the most commonly mentioned **challenges** for mental health carers in Queensland.

1. **The financial impacts of caring** – Despite two-thirds of the 305 respondents to a survey reporting that they receive a government support payment or allowance, almost three-quarters of the respondents had experienced financial hardship due to their caring responsibilities. A third of respondents worked fewer hours, or not at all, due to their caring responsibilities. The episodic nature of mental ill-health can create challenges for mental health carers in maintaining employment and accessing carer payments. In addition, carers often speak about the financial strain created by the high costs associated with mental health care, including appointments, medication and transport.

2. **Impacts on carers' mental, emotional and physical health and wellbeing** – Almost half of the carer survey respondents reported that they experience mental ill-health themselves. Just over 40 per cent of respondents reported impacts on their emotional health, with the greatest likelihood of impact felt by those caring for a child with mental ill-health, those who are in the first year of taking on a caring role, older carers, and those who have been caring for more than 10 years. Caring responsibilities also impact on physical health and wellbeing and many carers are concerned about what will happen when they can no longer care.

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[9] Arafmi (2024). *At what cost: The experiences of unpaid mental health carers in Queensland 2023 – 2024.* p15-24 Available at A04-Arafmi-Consultation-Report_250624.pdf

3. **System navigation and advocacy** – Mental health carers frequently face challenges in navigating complex health and support systems, including the mental health system, the NDIS and Centrelink.

4. **Stigma and social isolation** – Whilst social isolation is a common experience for carers more broadly due to a lack of time for social engagement outside of their caring responsibilities, mental health carers often speak about feeling judged and misunderstood by others, including health professionals. The stigma associated with mental ill-health can make carers reluctant to seek help or speak of their experiences, exacerbating feelings of isolation.

The following were the most common themes amongst mental health carers as to **what would make a difference** to them in their caring role:

1. **Personal and practical support** – such as emotional support, practical assistance with daily tasks, respite, peer support and connection, family support, and support for carers' own physical and mental health.
2. **Financial assistance** – to cover the costs of caregiving and help to address the financial disadvantage experienced by carers across a lifetime.
3. **Information, education and training** – including assistance with navigating systems and services, information about mental health conditions and building of skills in advocacy and self-management of health and wellbeing.
4. **Improvements to the mental health system** – including better access to mental health services, individualised care for those with mental health conditions, cultural sensitivity and diversity in service delivery and long-term planning to ensure the people who mental health carers support are looked after into the future.
5. **Recognition by the mental health system and the wider community** – including recognition and understanding of the roles mental health carers play and greater collaboration and communication between carers and health professionals.
6. **Greater support for balancing work and caregiving responsibilities** – such as flexible work arrangements and workplace awareness and understanding of the demands placed on mental health carers.

"One thing that was missing was emotional support. While there were resources available for practical assistance, such as information and advice, there was a lack of support for the emotional challenges that come with being a caregiver. It would have been beneficial to have access to counselling or support groups to help navigate the emotional aspects of my caring role." (Statewide consultation participant)

Research conducted by Monash University and the National Mental Health Consumer and Carer Forum on *Mental Health Family Carer Experiences of COVID-19 in Australia* also provides an excellent set of short- and long-term recommendations for the Australian Government[10], which address many of the challenges identified in our statewide consultations.

Peer support

Our statewide consultations highlighted the challenges mental health carers face in relation to social isolation and lack of understanding of what it is like to care for someone experiencing mental il-health, by friends, the wider community and the health system.

"Having connections with other carer peers who had walked in a similar situation would have helped. I would have been able to learn from them and it would help me not to feel so alone or ashamed. I started to pathologise my 'caring too much' and feel crazy when the rest of my friends and community wished for me to have it easier. I was often encouraged to give up my caring duties, pushed to accept it as 'never going to get better', and judgements around my unwillingness to give up. This further isolated me and led me to fear that my caring was somehow shameful. Friends supported as much as they could but without a closer living experience of this, what was being offered as support actually was deeply disempowering to me at times." (Statewide consultation participant)

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[10] Available online at https://nmhccf.org.au/our-work/discussion-papers/report-mental-health-family-carer-experiences-of-covid-19-in-australia

"Some of the stories I have to tell, a lay person may not be able to reciprocate, hear comfortably, nor understand and appreciate in the ways I dearly need to feel seen, heard and safe." (Statewide consultation participant)

Several pieces of recent research have evidenced the value of the emotional and practical support that mental health carers and families gain from access to peer support workers and peer support groups. For example:

Carer networks and carer support workers in hospitals and community family peer support services were highly valued. Both for the information and service navigation they assisted with but also for the sense of connection, practical assistance and hopefulness that arises from speaking with someone who has shared experiences.

Similarly, independent carer support groups and the actions of carer peak bodies were highly noted as being valued and beneficial to family. The sense of support and understanding heard when talking to people who have experienced or are currently experiencing what you are was prime to family feeling able to carry on.[11]

Reflecting on all carers

In addition to the importance of the National Carer Strategy reflecting the specific challenges and needs of mental health carers, Arafmi is cognisant of the importance of taking into account the needs of specific groups of mental health carers, such as young carers, ageing carers, male carers, and carers in First Nations, LGBTQIA+, Culturally and Linguistically Diverse and rural and remote communities. Consideration also needs to be given to how caring responsibilities are shared within, and impact upon, family and kin groups, as well as individual primary carers.

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[11] Petrakis, M. and Walters, C. (2022). *Mental Health Family Carer Experiences of COVID-19 in Australia: Final report* for the National Mental Health Commission from the NMHCCF as part of the Pandemic Grants for Priority Groups. Melbourne: SWITCH Research Group, Monash University.

Young carers require particular attention. Through Arafmi's work with a network of young carer support services in Queensland and research by Griffith University that we co-funded[12], we know that children as young as 4 years old are assuming caring responsibilities for their parents, creating implications for participation in education and social interactions, and potential child safety concerns. Not surprisingly, this group of carers often stay hidden and unsupported.

A recent evaluation of a Carer Gateway funded Young Carer Program by the Centre for Social Impact at the University of Western Australia, found that the program team often needed to address young carers' basic, immediate living needs, rather than doing early intervention and capacity building work that they had anticipated. They also noted a lack of services for young carers under the age of 14 years and the need to advocate for young carers at a systems level, including within the education system and State parliament.[13]

Additional national research and data collection related to specific carer groups may be necessary to gain a better understanding of needs. Therefore, it will be essential for the National Carer Strategy to include data and research activities that will provide information to guide planning and decision making into the future.

There may also be a need to revisit the definitions of carers and primary carers used in legislation and policy, to accurately reflect the diversity of carers and caring responsibilities.

Recommendation 6.
The National Carer Strategy should include strategies for meeting the specific needs of particular groups of carers, including a national research and data gathering component to ensure these specific needs are understood, addressed and appropriately reflected in legislation and policy.

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[12] Hutchings, K., Harris, N., McMillan, S., Radford, K., Slattery, M., Spencer, N., & Wheeler, A. 2021. *Young Carers in Australia industry research report*, Griffith University: Brisbane, Australia.Available at YC-Report-V2-DIGITAL-02112021.pdf (griffith.edu.au)

[13] Lester L., Scullin B., Lester R., Zou S., & Flatau P. (2024). *Evaluation of the Young Carers Program*. Perth: Centre for Social Impact, The University of Western Australia. https://doi.org/ 10.60836/b5r3-pf85

Payments

Feedback from mental health carers in our statewide consultations and annual carer survey, and our carer support services has highlighted the challenges carers face in accessing carer payments. This can be due to lack of awareness of available payments, misinformation that leads carers to assume that they won't be eligible, and difficulties in navigating the complexities of eligibility and application requirements, particularly when carers are already highly stressed and stretched and when they have language or literacy barriers.

Arafmi is developing a new monthly information session and resources for mental health carers to help them understand carer payments and application processes and where to get further help if needed. It would be valuable for the National Carer Strategy to consider what similar supports can be provided for carers on a national basis.

Carers have also spoken about the inadequacy of carer payments to cover living expenses, and medical and transport costs in situations where their caring responsibilities prevent them from engaging in paid employment. The statewide consultations revealed stories of carers having to choose between paying for their person's care needs or covering basic expenses like rent and food, as government allowances were insufficient to cover both.

According to Carers Australia, Income Support through the Carer Payment is equal to only 28 per cent of weekly ordinary time earnings for singles in Australia, or 21 per cent of weekly ordinary time earnings for couples in Australia.[14]

Carers have made comparisons between payments to disability support workers who support someone with a psychosocial disability and carer payments to someone providing the same kind of support (but unpaid) to a person who is unable to access NDIS supports.

The 2023 report of the Senate Select Committee on Work and Care highlighted the effect that caring has on financial wellbeing, particularly for women, who continue to carry the majority of caring responsibilities:

> ***"It explains the very wide gaps in lifetime earnings for workers with caring responsibilities and it casts a long shadow into retirement for many working carers and women who, after a lifetime of work and care, enter a retirement of poverty."***[15]

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[14] https://www.carersaustralia.com.au/superannuation/

[15] The Senate Select Committee on Work and Care (2023). *Final Report*. Commonwealth of Australia. pxxv

Research conducted in 2016 by the University of Queensland on behalf of Mind Australia found that “the total annual replacement cost for all informal mental health carers in 2015 was $14.3 billion. After adjusting for $1.1 billion offset in Centrelink payments, this figure was $13.2 billion. This is how much it would cost governments to replace all of the caring tasks currently provided by mental health carers with formal mental health support services, such as PHaMs or disability support workers.” The research conservatively estimated that government expenditure on mental health carer services in the same year was approximately $1.2 billion.[16]

This evidence suggests that it is time to revisit the adequacy of carer payments and allowances, particularly in light of the significant gaps in psychosocial supports that continue to be met by the efforts of unpaid mental health carers.

Recommendation 7.
The adequacy and fairness of carer support payments should be reviewed against the current economic environment and the context of availability of alternatives to the provision of unpaid care. The review should also consider the addition of superannuation on carer support payments to address the financial inequalities created over significant periods of caring.

5. Conclusion

Arafmi supports the development of the new National Carer Strategy as a first step in improving the situation of mental health carers. Ideally the strategy will set the foundation for deep and broad reform across the many areas of legislation, policy and service delivery that impact upon the lives of mental health carers.

We appreciate the opportunity to highlight the particular challenges and needs of mental health carers and share our ideas for how the strategy could help to address these, and we would welcome further discussion on any of the issues we have raised in this submission.

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[16] University of Queensland School of Public Health (2016) *The economic value of informal mental health caring in Australia: summary report*. Commissioned by Mind Australia