



Arafmi Ltd and Carers Queensland: Joint Submission for Mental Health Select Committee

*Inquiry into the opportunities to improve
mental health outcomes for Queenslanders*

Arafmi Ltd and Carers Queensland are pleased to provide this joint submission for the consideration by the Mental Health Select Committee. As two key carer organisations in Queensland we have direct contact with carers across the whole state, actively identify carers needs and promote for these to be understood and met across all levels of government. Arafmi and Carers Queensland are providing this as a joint submission to highlight a number of key opportunities for carers of people with mental health needs which both organisations strongly support.

Arafmi Overview

Founded in 1976, Arafmi Ltd is a not-for-profit organisation that provides support to people who have a mental illness, their families, and informal/unpaid carers in Queensland (QLD).

Arafmi Ltd delivers supports in QLD that:

- provide emotional and therapeutic support to people who live with mental illness and families, unpaid carers, and friends of people who experience mental illness via 1-1 support, counselling, group support and respite;
- provide systems advocacy to convey the needs of unpaid carers to healthcare professionals, the Government, and the general community;
- offer information and educational support to unpaid carers to cope with the demands and pressures of caregiving;
- increase community awareness and understanding of mental illness; and
- decrease the stigma attached to mental illness.

Funded by Queensland Health Mental Health, Alcohol and Other Drug Branch (MHAOD) and the National Disability Insurance Scheme (NDIS), Arafmi provides support to over 1000 people who experience mental illness, mental health carers, and families annually. This support is provided by a team of 170 employees and 40 volunteers.

Carers Queensland Overview

For more than 30 years, Carers Queensland has been working to advocate for equal rights, opportunities, and enhanced outcomes for families. Carers Queensland is the voice for carers and our work reflects the diversity of the community we support.

Recognising that all individuals and caring situations are unique, we aim to provide services that are respectful and inclusive of all carers throughout Queensland, at every stage of life. We are committed to working alongside every community and caring family, including LGBTI and Aboriginal and Torres Strait Islanders, to improve support and advocacy services for them.

We continue to build on our strengths to ensure we support all carers in achieving their goals, enhancing their relationships, and living the life they want. We are dedicated to making life better.

Carers Queensland services include NDIS Local Area Coordination Partner in the Community Program, Carer Program, Your Caring Way Program and Registered Training Organisation.

¹ Dominic, S, Heilscher, E, Lee, Y Y, Harris, M, Schess, J, Kealto, J & Whiteford, H, 2017, The economic value of informal mental health caring in Australia: summary report, viewed 9 January 2022, https://www.mindaustralia.org.au/sites/default/files/publications/The_economic_value_of_informal_mental_health_caring_in_Australia_summary_report.pdf



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Arafmi Ltd Chief Executive Officer (Irene Clelland) and Carers Queensland Chief Executive Officer (Debra Cottrell) are appointed members of the Queensland Carers Advisory Council. The Queensland Carers Advisory Council is established under the *Carers (Recognition) Act 2008* to provide advice to the Minister for Seniors and Disability Services and Minister for Aboriginal and Torres Strait Islander Partnerships on work to promote the interests of carers and make recommendations to support carer recognition.

General Position

Arafmi and Carers Queensland acknowledge that whilst there are funded programs in place to support carers of people with mental illness or mental health supports needs, Queensland Government should consider investing in additional measures to support carers in the following areas:

1. Individual and system advocacy, through the establishment of a mental health carer peak body. The 'Peak' should be designed and managed by people who have a lived experience of a mental health caring role
2. The 'Peak' should have close alignment to the newly established Mental Health Lived Experience Peak Queensland, including comparable funding.
3. Investment in 'respite' opportunities for carers that will support carers to maintain their caring role
4. Increase the lived experience workforce by increasing investment in statewide consumer and carer representatives and other peer roles
5. Additional programs to support carers to continue to participate in the workforce

Mental Health Carers save the Australian economy approximately \$15 Billion per annum¹. It is estimated there are approx. 500,000 carers in QLD. The above measures have the potential to:

1. Reduce mental strain on carers
2. Increase awareness of the carer role, thus increasing early intervention opportunities
3. Positively impact the QLD economy through
 - a. Increased participation in the work force
 - b. Continuation of the carer role, reducing the need for other funded services

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Carers of people with mental health needs

Carer Profile

The term “Carer” is commonly used to describe people who provide support to individuals who need assistance. A carer may be primarily the person’s partner, son, daughter, parent, grandparent, neighbour, friend or, in some cases, their child or children.

Carers may live with the person they are caring for or visit the person regularly. They can provide a range of supports including emotional and social support throughout the day, assistance with practical tasks and daily living. Carers are people who invest variable levels of time, energy, and support, generally in an unpaid capacity. Carers are often ‘hidden’, may not see themselves as a carer and /or are not identified and supported by services and communities. Children who become carers face particular difficulties in being recognised and having their needs met.

More specifically, carers supporting children, adolescents or adults with mental health needs: -

- Can be caring for more than one person and with more than one need e.g. mental health needs, drug and alcohol needs, physical needs, aging relatives and children;
- Can be working, have their employment at risk or unable to engage in work because of their caring roles which can be episodic and intense;
- Can be school aged or attending tertiary education. The caring role can significantly impact on young people’s own mental health and their ability to engage in education and complete study. This can then lead to difficulties gaining and maintaining employment;
- May be experiencing financial hardship and not have access to funds to pay for assessments, psychiatrists, clinicians and medications;
- May have unstable housing and be at risk of homelessness;
- May have more than one relationship impacted by their caring role including breakups in families and losing a partner;
- May have no choice about taking on a carer role and not have the skills or supports to prepare them for this often lifelong role. Young people caring for a sibling or other relative with mental health needs can have a primary carer role for all of their life which can impact all aspects of their future including their own mental health, relationships, education, work, finances and housing;
- May have no choice but to meet the health, social, emotional and financial needs of the person they care for as formal supports are not readily available for them to access. This is particularly relevant in regional and rural areas.
- May have limited or no knowledge of supports and services including acute mental health services, community supports, mental health plans, carer supports and the NDIS;
- May be in crisis and experiencing high stress when they initially make contact with a service
- May be supporting someone who has lifelong, episodic and reoccurring mental health needs which can be unpredictable and put themselves or others in their home at risk
- May not be consulted or involved in decision making and planning relating to the person they support

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- May be at risk of developing significant mental health needs themselves due to stressors as shown above.

Carer Needs

Awareness of Carers

There is a broad lack of awareness in the community, places of education, workplaces and services about who carers are, their needs and the long-term impact the caring role has on relationships, families, housing, education, work, finances and individuals own mental health and general health. Additionally, carers of people who live with mental illness can be less visible than other types of carers due to; Societal and personal stigma surrounding mental illness, lack of awareness of the relationship being an unpaid caring role, the episodic needs of a person who lives with mental illness (and as a result their care needs). This leads to carers not being identified and supported and involved in planning for the people they care for.

Access to Information

People with mental health needs and carers of all ages require information and support to navigate and access timely assessments, interventions and services. This needs to be readily available, easy to find and in a range of formats that are accessible for people of diverse needs including people of culturally and linguistically diverse backgrounds.

Access to Services

Access to affordable, safe, responsive local services is required for people with mental health needs and carers. This includes the ability to access:

- a psychiatrist and mental health clinicians face to face and online without extensive wait periods and fees
- “Safe Spaces” for assessment and support as an alternative to emergency department
- a range of services across Queensland including acute services, community services, suicide prevention, integrated mental health alcohol and other drug services, post discharge follow-up and support including when leaving prison, advocacy and housing including short term accommodation with supports for recovery and stabilisation
- services to coordinate referrals and access requests for funding like the NDIS
- a dedicated case manager who can work with a person individually as needed to support recovery, access services, build community connections and networks, engage in employment and maintain stable suitable housing.

Carer Involvement and Consultation

This is required when:

- designing new models and services and reviewing existing services. Involving carers in codesign from the beginning to the end of the project can achieve a range of positive outcomes
- making decisions, assessments and plans for individuals with mental health needs. This includes involving carers at all possible points when a person they care for is engaging with services. When carers are not involved the individual, carer and or other family/support networks can be left in unsafe situations in the community and individuals health, employment, housing and finances significantly impacted and at risk.

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Respite

Carers experience significant levels of stress and can have limited or no opportunities for respite or a break. Through nationally funded programs there are some limited funded day and overnight respite options in some areas of Queensland. If the person with mental health needs doesn't have access to funded supports e.g. through NDIS or is reluctant to access supports the carer can be left without a break for long periods even years. Lack of access to adequate and affordable respite can lead to carer fatigue, relationship breakdown, increased mental health needs for carers and, at times, family violence.

Opportunities for Improvements

Awareness campaign for the whole community, in education, workplaces and health services to know:

- who mental health carers are including young carers
- how, when and why they need to be identified and supported
- signs of carer strain and distress
- what supports are available
- how to provide carer inclusive practices

[A practical guide for working with carers of people with a mental illness | Mental Health Australia \(mhaustralia.org\)](https://mhaustralia.org) was produced in 2016 and is a valuable document to assist organisations and individuals to develop care inclusive practices.

Standardise practices across industries and sectors to identify carers and consider their needs e.g. at the point of intake in education, housing, health services.

Increase the availability of **information and supports** for carers and people with mental health needs so they can know their rights, understand how systems work, know how to navigate complex mental health systems, know where to go and can directly access the correct services and interventions as required in their local areas and/or online e.g. through primary health care providers, mental health and service navigators, carer agencies, guidance officers, carer peer workers, employee assistance programs, human resource teams in workplaces and state members offices.

Expand lived experience workforce across the state. In parts of Queensland there are specific carer peer workers and consumer peer workers available to provide information, support and assistance navigating systems. These roles have been invaluable for carers, people with mental health needs and clinicians. The peer workers significantly reduce unnecessary stress, ensure people know what services are available, link people with services and supports as early as possible and this leads to a range of positive outcomes. These roles don't exist in many parts of Queensland or there will be one worker covering a large geographical area.

Carer involvement and consultation could become a standardised part of practice and models across organisations and branches. This would ensure carers and people with lived experience are consistently part of codesign from the beginning to the end of processes and not just occasionally included in focus groups.

Standardising practice for considering and initiating carer involvement and consultation with assessments, planning and decision making for the person the carer is supporting. At all key points of contact and access with services in the community and hospital carer inclusive practice could be developed and implemented.

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This would ensure carers are considered, their views sought and involved in planning and decision making where possible and appropriate. This will assist clinicians to make informed decisions, improve individuals' outcomes and lead to the minimisation of risks for carer, the person they are supporting and others.

Establish **independent carer advocacy** roles. There is no designated role to provide individual advocacy for carers. There are specific disability advocate roles covering parts of Queensland and these positions are not able to support carers. Independent carer advocates would meet a large service gap, reduce carer strain, significantly improve outcomes, treatments, and recovery for people with mental health needs and contribute to a reduction on demands on services

Funded respite for carers of all ages across Queensland. This includes being able to have a break in their own home, for a few hours regularly and/or for time away from their caring role and situation overnight. Respite is essential to the ongoing positive wellbeing of mental health carers and should include expanded funded opportunities for carers from diverse demographics, including carers who are culturally and linguistically diverse, live in rural or remote areas or are Aboriginal and/or Torres Straite Islanders. Diversity in design for respite must be considered to ensure there are accessible opportunities for all carers.

Establishment of a carer designed and led Lived Experience peak body:

In 2018 and 2019, Queensland Health commissioned a series of consultations to inform the development of a new mental health consumer representative peak organisation. This included a consultation by Health Consumers Queensland (HCQ) with people with a lived experience of mental ill-health, their carers and families. This peak was established in 2021 and is in the process of developing its ongoing strategy. Whilst carers and families were involved in the development stage of the peak and there is a strong and positive collaborative relationship between the peak and carer representative organisations there is a gap in systems and individual advocacy for mental health carers.

The implementation of a similar peak body specifically for mental health carers, will ensure that the opportunities addressed in this submission will be led by an independent, lived experience run body.

Arafmi Ltd and Carers Queensland look forward to discussing this submission with the Select Committee on Friday 18th February 2022.

Irene Clelland - CEO Arafmi



Debra Cottrell – CEO Carers Queensland



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