Who Cares for the Carers:

Improving the Wellbeing of Mental Health Carers

A Case Study in the Illawarra Region

Freda Hui and Mona Nikidehaghani

UNIVERSITY
OF WOLLONGONG
AUSTRALIA

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Foreword

This report examines the experiences of mental health carers in the Illawarra region NSW. A sample of carers, who were registered clients of One Door Mental Health (ARAFMI Illawarra) between January 2018 and June 2020, were asked a series of questions and the results analysed. The research presented in this report is not intended to provide a comprehensive analysis of issues related to mental illness, but rather has a deliberately narrow focus on the experiences of the carers.

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List of Abbreviations

BPD	Borderline Personality Disorder
CAC	Carer Advisory Committee
CMO	Community-Managed Organisation
DSP	Disability Support Pension
FACS	Family and Community Services
JH&FMHN	Justice & Forensic Mental Health Network
LHD	Local Health Districts
NDIS	National Disability Insurance Scheme
PTSD	Post-traumatic Stress Disorder
UOW	University of Wollongong

Executive Summary

We report on interviews conducted to improve the wellbeing of mental health carers. Our aims were to investigate the main issues affecting mental health carers, to evaluate the outcomes of current programs organised by One Door Mental Health (ARAFMI Illawarra), and to provide recommendations to improve the wellbeing of carers. Our interviewees are 'hidden workers', a cohort that is under-appreciated by society. Some of our key findings were that many of our carers felt isolated, had limited support, faced financial burdens, and lacked an understanding of mental illness. More than half of them developed mental health disorder themselves. Our analysis shows that current services improve mental health carers' social life and mental health. Education programs can also empower them to have more control over their lives and equip them to manage crises. We propose a number of measures to help improve the wellbeing of carers.

Recommendations:

1. Increase funding for non-profit organisations to deliver flexible support programs for carers to attend.
2. Advocate for mental health carers to access governmental support.
3. Organize more support groups and counselling services.
4. Provide ongoing information sessions and educational programs.
5. Develop a mobile application tailored for mental health carers.

Section One: Overview

The experience of mental illness not only affects the individual but also those who care for them. In Australia, approximately 240,000 people care for someone with a mental illness (Mental Health Carers Australia, 2019). Research shows that their families, partners and friends make a significant contribution to the Australian mental health workforce by providing unpaid direct and indirect services to their loved ones. These carers experience significant emotional, health and financial issues and are at risk for developing mental health disorders themselves (Flyckt et al., 2013; 2015 ; Gelkopf & Roe, 2014; and Souza et al., 2017). However, the focus of the majority of services provided in Australia is on the person with the mental health condition (New South Wales Government, 2019). According to ABS (2015), 59% of mental health carers in NSW did not receive a government carers allowance. Carers NSW Australia (2016) has indicated that many people in caring roles do not identify as carers, and are therefore often not entitled to services and supports that can assist them. With limited financial and non-financial support from the government, services provided by non-profit organisations are a vital source of support for these 'hidden workers'.

1.1 Mental Health Carers

The Australian Government (2020) suggests that 1 in 5 Australians will experience mental illness at some point in their life, and their friends or relatives are the ones who provide unpaid care and support for them. According to Carers Australia (2020), one third of 861,000 primary carers – those who provide the most informal support to their loved ones – provide 40 hours or more of unpaid care per week. The majority of primary carers are women, and they look after someone with mental health illness.

A mental health carer is a person who is a family member or friend who plays an important role in supporting their loved ones with mental illness. According to Mental Health Carers Australia, carers may not consider themselves as a carer because they see it as part of their relationship. Carers often provide social and emotional support for their loved ones, as well as managing doctors' appointments, finances and dealing with crises.

Despite the significant role of carers in the support and recovery of people with mental health problems, their contribution is often not recognised by governmental programs (NSW Government, 2020). The New South Wales Ministry of Health has acknowledged the need to support mental health carers (NSW Carer (Recognition) Act, 2010). In New South Wales, support for families and carers of people with mental illness is available through the NSW Family and Carer Mental Health Program. The aim of this program is to include carers in the care and recovery goals of their loved ones; provide evidence based, cost effective, and timely support and information for carers; and include carers in the planning, development and evaluation of services. This program works as a partnership between 15 Local Health Districts (LHD), the Justice & Forensic Mental Health Network (JH&FMHN) and five specialist Community-Managed Organisations (CMOs):

- Aftercare
- CatholicCare Wilcannia-Forbes
- Mission Australia
- One Door Mental Health
- Parramatta Mission.

1.2 Aims of this report

The aim of this report is to improve the wellbeing of mental health carers. In order to do this, we first investigate the social needs of mental health carers, and then evaluate the social outcomes of current programs in the Illawarra region. Working in collaboration with one of five specialist community managed organisations, One Door Mental Health (One Door), we aim to evaluate the outcomes of their current programs for mental health carers in the Illawarra region.

Section two follows with an introduction to our research partner, One Door Mental Health/ARAFMI Illawarra, and a description of our research method. The sample of ARAFMI clients that were interviewed is also presented, along with their demographic information, loved ones' mental illnesses, and support services currently accessed. Section three presents our findings from the interviews, categorised into two key areas: challenges and outcomes of

the programs. Section four discusses the Outcomes Framework for mental health carers. Lastly, recommendations are offered in Section five.

Section Two: A Case Study of Mental Health Carers in the Illawarra Region

2.1 The project

This joint research project involved a team of UOW researchers and One Door Mental Health (ARAFMI Illawarra) staff. This project was a pilot study that aimed to improve the wellbeing of mental health carers in the Illawarra region, particularly as it related to carers who had attended workshops and received support from ARAFMI Illawarra.

One Door Mental Health is a non-profit organisation funded by NSW Health. They provide services and advocacy support for people living with mental illness and their families (One Door Mental Health, 2020). Many of these carers do not have any carers allowances from the government and rely on local community support. As such, ARAFMI was a point of contact for identifying people in the Illawarra region who may require assistance as carers. Potential interviewees were invited to discuss their caring role and experiences with ARAFMI's services.

The project team interviewed 27 ARAFMI Illawarra clients via Zoom or phone. These clients were each interviewed for approximately one hour, and were asked a range of open-ended questions concerning their personal situations and support needs. All interviewees were provided with a gift voucher in recognition of the time that they gave to the interviews.

Appropriate ethics clearance for the project was obtained from the University of Wollongong Human Research Ethics Committee (2020/096), and appropriate authorisation to access the ARAFMI database was granted by One Door representatives. Given the sensitivity of these clients and respect for confidentiality, all phone communication was via an ARAMFI Illawarra representative.

2.2 One Door Mental Health (ARAFMI Illawarra)

ARAFMI Illawarra was formed in the Illawarra in 1982 with a committee of three. It then became a viable carer support service for the region. Since July 2019, it has merged with One Door Mental Health (One Door) as a carer program independent from government mental health services in NSW. It is currently staffed by two part-time employees who are supported by a strong group of carers who form the Carer Advisory Committee (CAC). It has in excess of 100 carers who are formal members of ARAFMI. They attend a variety of programs/activities which ARAFMI provide. These include support groups, recreational programs, education programs, retreats and morning coffee gatherings.

ARAFMI Illawarra has a sound reputation for providing assistance, support and advocacy to carers in the local and wider community. Although still small in comparison to some other local mental health organisations, ARAFMI Illawarra 'punches above its weight' in terms of innovation and the pursuit of continuous improvements to the lives of carers.

2.3 Outcomes Framework

Our approach to this research is both qualitative and empirical. We were guided by the NSW Government Human Services Outcomes Framework (Outcomes Framework) (FACS, 2017) to identify the challenges experienced by mental health carers, and to evaluate the effectiveness of programs and services for mental health carers. The development of outcomes measurement has traditionally been driven by the requirements of funding bodies, such as governments and social investors. There is global evidence (e.g. the outcome measurement policy and practices in the UK, Scotland, Australia, the US and Canada) of a growing need for community organisations to assess the social outcomes of their programs (Hall et al. 2003, Hendricks 2008, Pritchard et al. 2012). The NSW Government developed the Outcomes Framework, setting out population outcomes for the delivery of human services (FACS, 2017). They also encourage community organisations, such as One Door, to apply the Outcomes Framework and present evidence on the impacts of their services on the community's wellbeing (FACS, 2017). As shown in Figure 1, the Outcomes Framework consists of seven

outcome domains, namely Education & Skills, Economics, Health, Home, Safety, Empowerment and Social & Community (FACS, 2017).

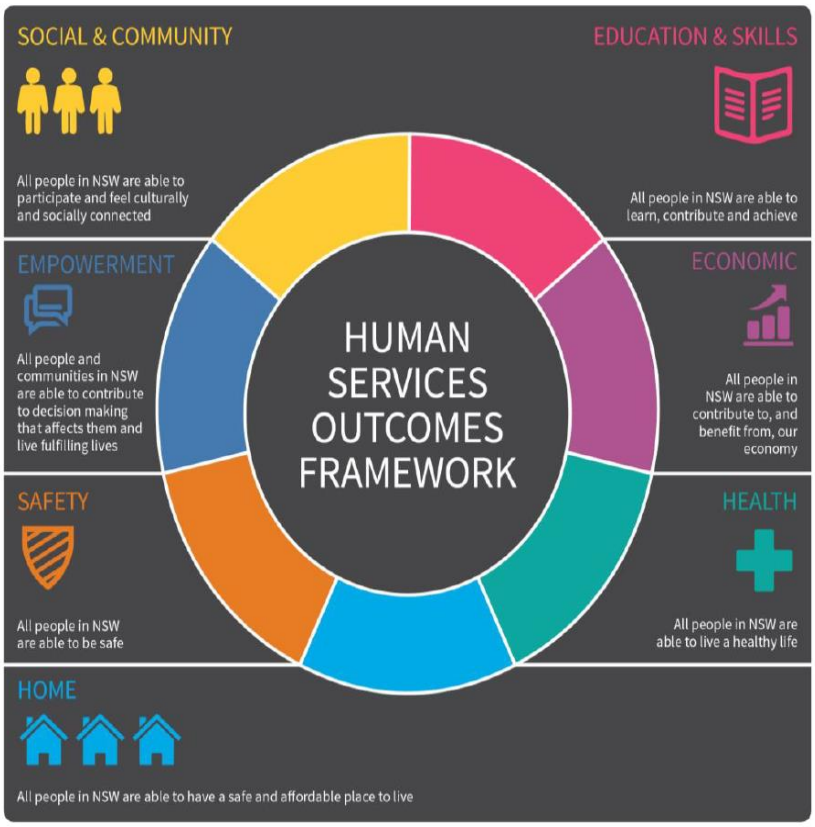

Figure 1 NSW Government Human Services Outcomes Framework (FACS, 2017)

For each outcome domain, the Framework articulates key outcomes and possible indicators to measure achievements. For example, outcomes for the Health Domain include improving mental health and wellbeing, and improving individuals' access to health care services they require (NSW Government, 2017). The 2017 Outcomes Framework is relatively new and the NSW Government has called for evidence to improve the framework, as well as identifying programs and interventions that improve wellbeing (NSW Government, 2017).

2.3.1 An Outcomes Framework for mental health carers

In our examination, we were guided by the Outcomes Framework to identify the challenges of mental health carers and to explore the social outcomes that are most relevant to mental health carers. The Outcomes Framework for improving the wellbeing of mental health carers consists of:

- Identifying the challenges experienced by carers based on evidence.
- Identifying the outcome domains expected from One Door Mental health.
- Impact pathways to achieve the outcomes based on evidence.

In order to identify the issues experienced by carers, we focused on seven outcome domains, namely: Health, Safety, Social and Community, Empowerment, Economics, Home and Education and Skills. Drawing on the challenges carers experience in their caregiving roles, we identified the most significant outcome domains for carers. For example, we noticed, due to the demographic aspect of our sample, the domain of Home was not relevant to this cohort. Additionally, while financial instability was an issue for carers, they did not expect financial services from One Door. Therefore, in analysing the outcomes of services delivered by One Door, we focused on five outcome domains including Health, Safety, Social and Community, Empowerment, and Education and Skills. The selection was also in accordance with the services delivered by One Door, which are mainly recreational services, short term and long term education courses, support groups, and social activities.

The NSW Human Services Outcomes Framework identifies a definition for each domain. In our examination, while guided by those definitions, we defined the key outcome for each domain as follows:

- Education and Skills: Carers are able to learn about mental illness, their roles and responsibilities, and develop skills they need in their caregiving roles.
- Safety: Carers feel safe in their caregiving role.
- Empowerment: Carers feel valued, confident and are able to control their lives.
- Social and Community: Carers feel connected to the community.
- Health: Improve carers' mental health.
- Economics: Carers have access to employment and financial resources.

The following section outlines the applied method and sample of this study.

2.4 Research method

The One Door Mental Health (ARAFMI Illawarra) database was reviewed and all clients who had received support from ARAFMI during 2018 – 2020 were selected as potential interviewees. A list of 55 potential interviewees was compiled, noting relevant details such as name, address, age, and phone number.

Invitations were sent electronically to each potential interviewee along with a participant information sheet, a consent form. An incentive in the form of a gift voucher was offered to potential interviewees. ARAFMI clients who agreed to an interview were contacted by an ARAFMI staff member/volunteer, and were provided with a choice of interview dates and venues (Zoom or phone interview). All interviews were coordinated by both UOW research and ARAFMI Illawarra staff members, and in many instances reminder phone calls were made. Interviews were scheduled over a three week period (12 Sep – 2 Oct 2020) and each lasted for about an hour.

Interviews were semi-structured and conducted by two members of the UOW research team. At the beginning of each interview, the interviewers clarified the purpose of the interview and confirmed key points that had been noted in the UOW participant information sheet and in the consent form, namely that: participation was voluntary; the interviewee could ask any questions about the research; the interviewee could decline to answer any questions; the information would be kept confidential; all identifying information would be removed prior to publishing; and that the interview would be recorded and transcribed. If requested, the interviewee could ask to see a copy of the transcript.

Interviewees were asked a range of open-ended questions drawn from a pre-prepared list, loosely grouped around personal details and circumstances, the nature of the mental illness, disabilities, difficulties as a carer, and experiences with ARAFMI and the mental health system. Interviews were recorded and later transcribed using Rev.com. Notes were also taken during each of the interviews. The interview transcripts and notes formed the primary data set for the project. Transcripts were reviewed by the UOW research team, with relevant details transferred to an Excel spreadsheet for analysis and supplemented with notes in cases where the recordings were unclear. Data was analysed in terms of themes, and attention was given

to the more nuanced responses of individual participants. A discussion of aggregate and individual responses is presented in Section 4.

2.5 The sample

As indicated, 27 people participated in semi-structured interviews with the research team. A brief outline of the interviewees is provided in the following sections.

2.5.1 Demographic details of the sample

Figures 1 and 2 show the age and gender profiles of our interviewees. Over 44% were aged between 55 - 64, with a substantial portion (40%) in the over 64 age bracket. Not surprisingly, almost 90% of the carers are women and retired. It is noteworthy that all participants cared for someone younger than themselves (see section 2.5.2 for profiles of the person with mental illness).

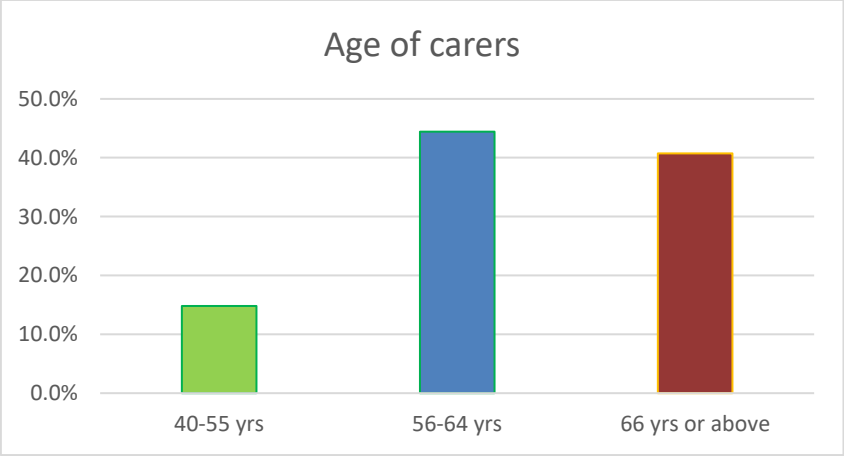

FIGURE 1 Age profile of interviewees

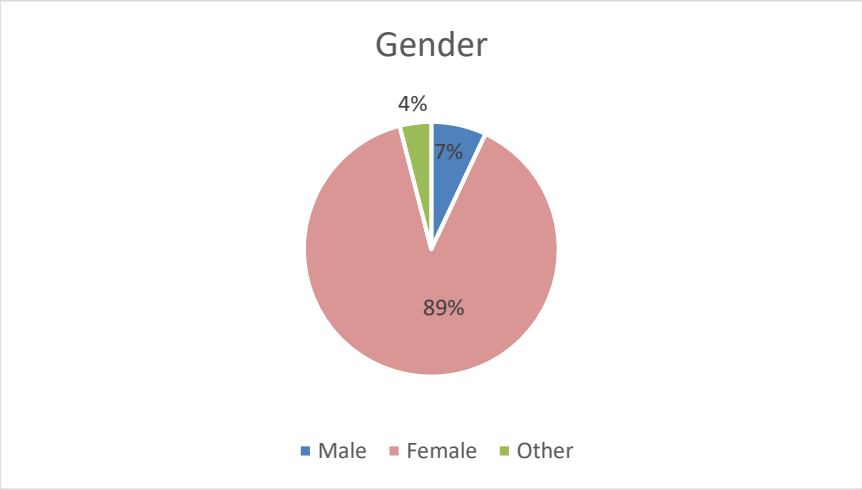

FIGURE 2 Gender profile of interviewees

2.5.2 Profiles of the loved ones

The majority (63%) of the carers are living with their loved ones who have mental health problems. The types of mental illness that their loved ones have include: Anxiety/Depression, Borderline personality disorder (BPD), Bipolar, Psychosis, Post-traumatic stress disorder (PTSD), and Schizophrenia. Some of them have a more complex diagnosis, with multiple mental disorders (see Figure 5).

As shown in Figure 4, most of the carers' loved ones are below 44 years old and only 17% of them are on the NDIS. Some of them are deemed to be eligible for governmental supports, however, due to their mental health issues, they did not apply for the National Disability Insurance Scheme (NDIS) or Disability Support Pension, and therefore financially rely heavily on their carers.

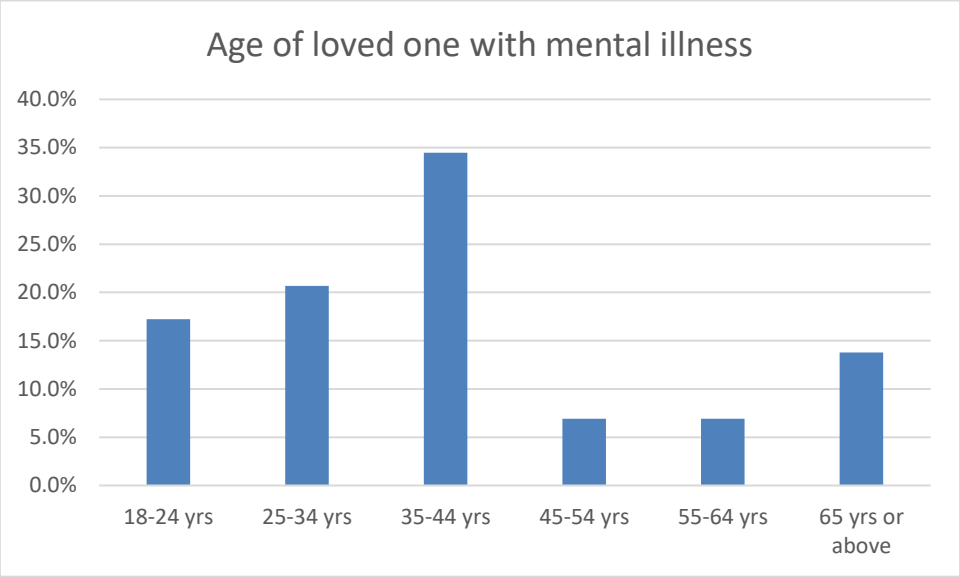

FIGURE 3 Age of loved one with mental illness

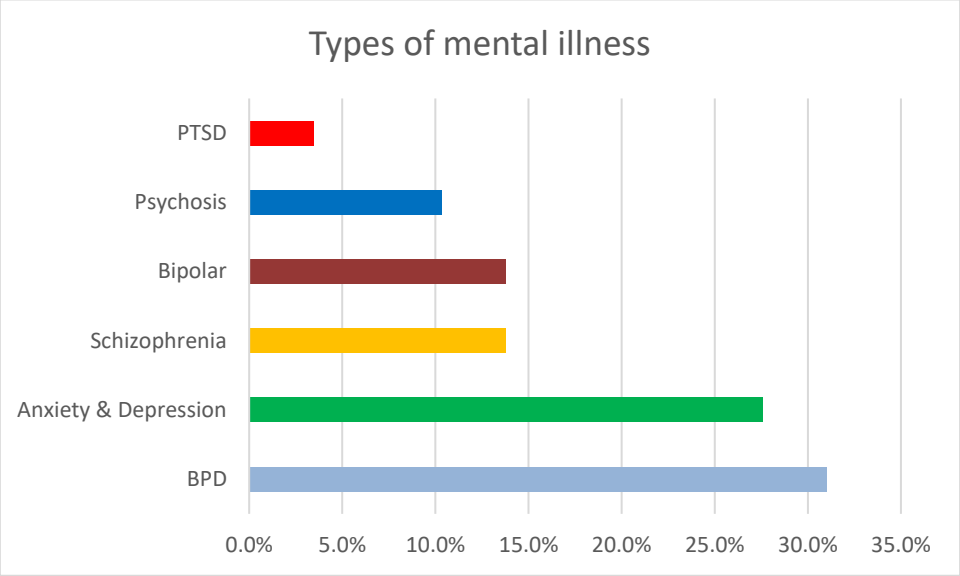

FIGURE 4 Types of mental illness

2.5.3 Contacting One Door (ARAFMI Illawarra)

When we asked the participants about how they first discovered the services provided by One Door (ARAFMI Illawarra), more than half of them found ARAFMI's services via friend's referral or by searching online. Some of them were recommended by South Coast Private Hospital or

by psychologists when their loved ones were in crisis. They expressed their concern regarding insufficient promotion and advertisement of ARAFMI.

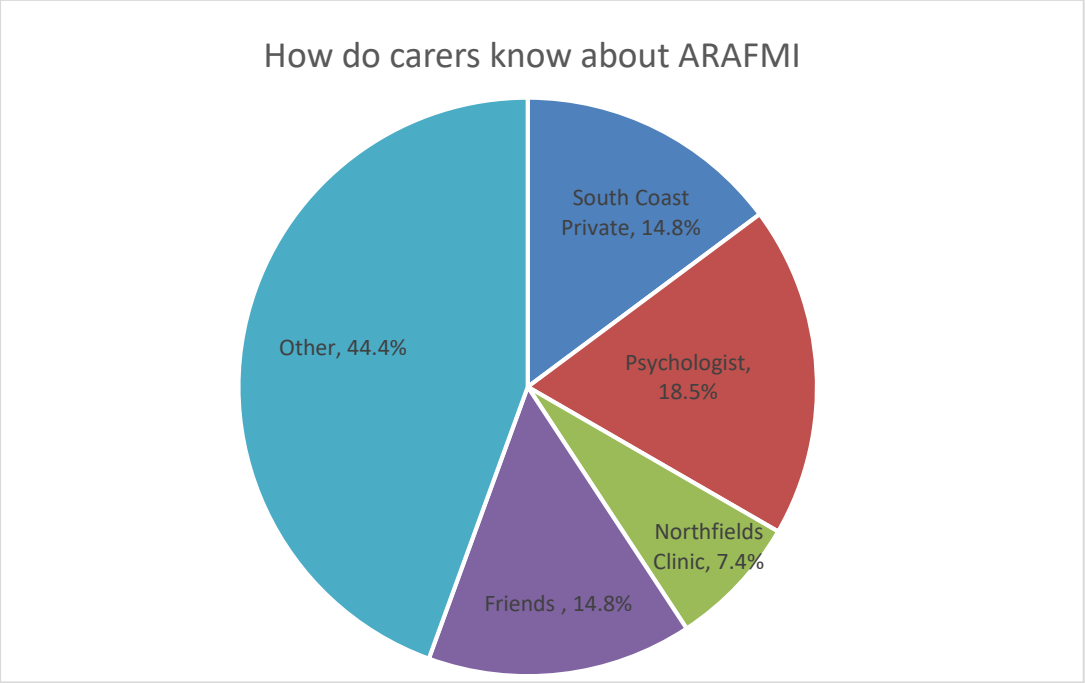

FIGURE 5 How do carers know about ARAFMI

2.6 Summary

This collaborative project between One Door Mental Health (ARAFMI Illawarra) staff and UOW led to the interviews of 27 clients drawn from the Illawarra database. These interviewees are currently looking after loved ones with mental illness. However, only 3 out of 27 currently receive carer allowances from Centrelink. While our interviewees experience significant stress and emotional burden, they are also disadvantaged by financial burdens due to their caregiving role. The participants in our sample draw on a limited range of supports and services in the region. Importantly, there is lack of public awareness about the services available for carers. Given this, carers support programs might be more effectively implemented if initiated through local community, and there is clearly a need for more effective means of communication about the services that are available.

The interview responses are analysed in detail in Section Three.

Section Three: Findings

Our interviews with 27 One Door Mental Health carers residing in Wollongong revealed a number of problems associated with being mental health carers. Our findings focus on two key areas, which include challenges of carers outcomes of ARAFMI's program for carers.

In the subsections that follow, we discuss our findings in detail, beginning with challenges carers experience in their caregiving roles.

3.1 Challenges

Participants identified eight key challenges they face when caring for someone with mental illness. These challenges include:

- Insufficient support
- Negative impacts on carers' mental health
- Being excluded from discussions with health professionals
- Financial burden
- Carers' lack of understanding of mental illness
- Fear of harm by their loved ones
- Social isolation
- Lack of control over life

In the subsections that follow, we discuss challenges in detail, beginning with insufficient support.

3.1.1 Insufficient support

The majority (17 out of 27) of the participants indicate that there is not enough support and services for mental health carers. The effects of this lack of support are exacerbated during public holidays, especially Christmas and New Year. While some carers indicated that there are some support services available in the Illawarra region for mental health carers, they noted lack of communication regarding types and places of support. Moreover, the burden and stress placed on carers made them vulnerable when seeking help, as indicated by one participant:

> *When you're in in this state of shock and disbelief. You have obviously been living in a whirlwind in, in a tornado. Prior to that, not knowing what's going on…because you're living with someone with mental health. You are scared and you don't know where to look. The rung of the ladder is to find support for yourself and you don't know what's going on. (Participant no. 13)*

Carers also identified the significant reliance on services provided by volunteers in community organisations and pointed to the lack of governmental funding for mental health carers services. Despite the fact that the federal government has recently increased funding for the mental health sector, mental health carers' wellbeing is typically a neglected aspect of mental health. As asserted by one participant:

> *They don't support carers with a mental illness as much as they support other tiers with physical disabilities. I think mental health kind of gets at the bottom of the pile. (Participant no. 17)*

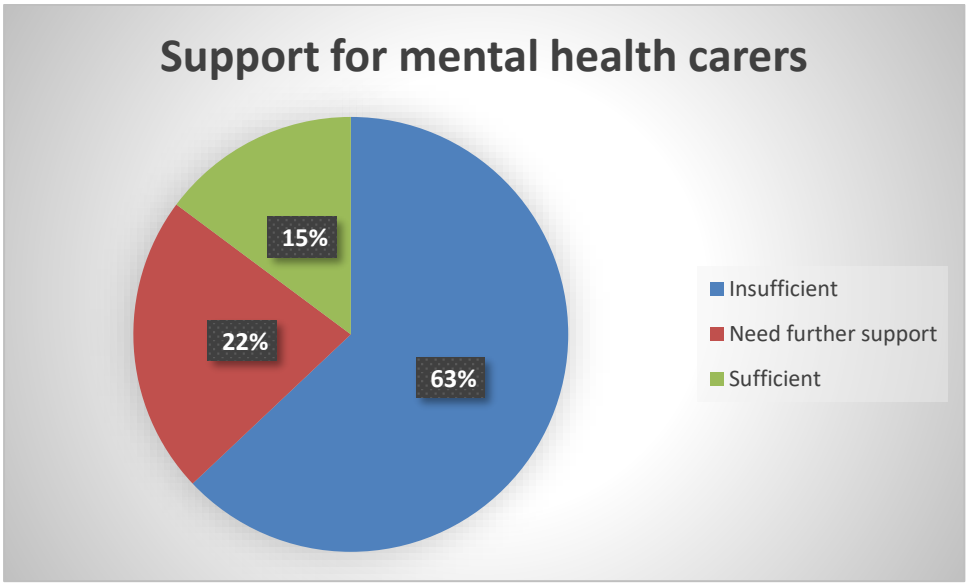

FIGURE 6 Support for mental health carers

3.1.2 Negative impacts on carers' mental health

Carers often experience significant emotional, health and financial issues, and are at risk for developing mental health disorders themselves. As indicated by one participant, caring for someone with mental health impacts their carer's health as well.

As a carer, you're obviously presenting as a strong person trying to seek help for this other person that it's not an obvious thing at that point that you need help as well. (Participant 13)

We asked participants to rank their mental health before attending the carers program from zero (being extremely unhealthy) to ten (feeling extremely healthy). Figure 7 shows carers mental health before accessing ARAFMI services.

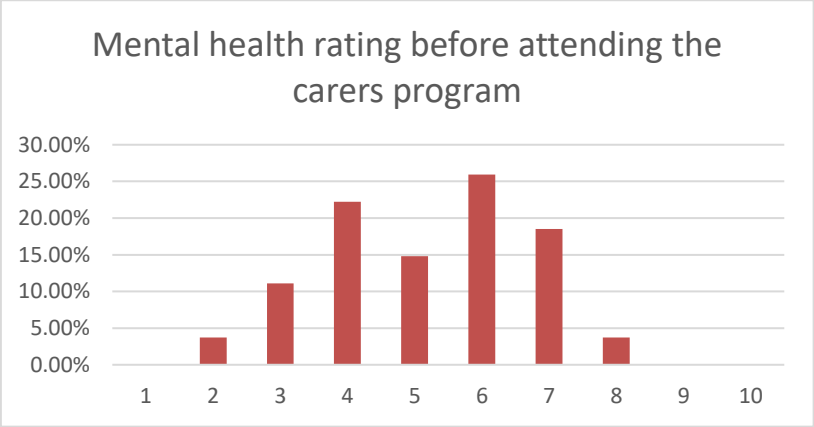

FIGURE 7 Mental health ratings before attending the carer program

Our findings indicates that majority of carers, 62% of our cohort, suffer from mental health issues such as anxiety and depression.

My husband and I both suffer from anxiety. (Participant no. 20)

I struggle quite badly with anxiety. (Participant no. 15)

My mental health deteriorated significantly… and I am on an antidepressant. (Participant no. 25)

Participants expressed that the physical and emotional demands of caring made carers vulnerable to mental health issues.

A lot of it is to do with [my wife]'s anxiety. My anxiety carries on from that, because I have to be her carer 100% of the time, because she's got agoraphobia. (Participant no. 16)

Stress in my life built up because I was a full time worker and I didn't understand distressful factor of having care for an extra person… have a big impact, a slow impact on me that I didn't realise till later. (Participant no. 6)

Not surprisingly, carers' deteriorating mental health impacted their care giving roles as well as their personal life.

Last year I had a reasonable amount of suicidality and having a partner with borderline and also the bipolar was actually really difficult, because all the time I was depressed. (Participant no. 18)

At times I've been at work and because of him, I get so much anxiety. I had to actually leave work. (Participant no. 19)

3.1.3 Being excluded from discussions with health professionals

Carers are frustrated because they are unable to discuss issues with medical professionals or get information from the people they care for. Even though carers have the fullest picture of their loved one's condition, mental healthcare professionals, such as GPs, are legally bound to protect the confidentially of their patients and are therefore unable to talk about care needs. This difficulty escalates if the loved ones they care for are adults. In some cases, carers were banned by their loved ones with mental illness from inquiring about information from the medical team.

My daughter banned me from speaking to the service providers or the treating team …. She doesn't take advice from me until there's a major catastrophe. (Participant no. 20)

The most difficult aspect from the outset is getting help when you absolutely know something is going wrong and you try to reach out to the medical profession. And they won't tell you anything. (Participant no. 21)

I didn't know what has happened when he was at the hospital. It's like your family member is in the hospital and you are separated and no one contacts you. (Participant no. 10)

3.1.4 Financial burden

Carers often provide financial support to their loved ones. Participants expressed the financial strain associated with caregiving. For example, carers felt obliged to pay for private insurance, as well as the fines, debts and living expenses of their loved ones with mental illness.

Being a carer comes with a financial cost, by a considerable amount. (Participant no. 11)

It is costly to see private psychologist. (Participant no. 2)

We've gotten them a car to get them to counselling and paid for the insurance. And then obviously we're still paying for their private health insurance. (Participant no. 13)

We paid off her car for her, but… she was constantly asking for money … we were always giving her money to move into new flats and things like that, because she moved all the time. (Participant no. 15)

> *I bought him a car, we paid for the repairs, the registration. He never had money, and we understood that. I actually found he was into marine rescue. I found a boat down the road, so I bought him a bought which helped him to focus…. any money he needed for counselling and anything else…. he went on holidays, etc. That came out of our money. (Participant no. 12)*

A majority of the interviewees do not receive any carers allowance from the government. Participants shared the financial impacts of providing support for their loved ones.

> *When she lived by herself in a unit, we were supporting her to be able to pay the rent. And that, that came out of our budget. (Participant no. 4)*

> *We end up paying the bills. So financially, it has hit us. It's eaten into our retirement income, but there's not much, what can you do? (Participant no. 27)*

Participants also indicated caring for their loved ones with mental illness impacted their careers and their ability to control their work and generate income. For example, many participants described occasions where their loved ones interrupted their work or times that they had to temporarily leave work.

> *When he goes off in brain he'll just ring or text lots of times at work. (Participant no. 2)*

> *When she's awake during the day, she'll ring me half a dozen times at least. And it's really distracting. And you just can't explain to her that you need to get to something, so I have to just pack up and take off. But it makes it really difficult because it is a very stressful job that I do. And I'm struggling to keep on top of it at the moment as it is. (Participant no. 24)*

> *I worked for a small company and so whenever I'd get a call where my son was, or if there was problems… we just had a deal that I would deduct the hours. So I was away from as long as I got the work done. (Participant no. 21)*

> *I have had to plead. Plead is a strong word. It's rather embarrassing. I liaised with my manager because I had to leave. If my daughter is in a crisis, I have to take time off. … I had to then expose myself to my manager [about my private life]. (Participant 20)*

A few participants indicated they had to retire to look after their loved ones.

> *When things were falling apart I retired. I don't know that I could have coped with working in the job that I had and being able to support her. So, I retired at 55. (Participant no. 4)*

> *I was running my own business when she became ill… We sold the business about the time she became very unwell. So I was sort of retired at the time. (Participant no. 7)*

3.1.5 Lack of understanding of mental illness

Carers mainly struggle with a lack of understanding of mental illnesses such as bipolar and BPD. Without an understanding of the nature of mental illness, it is difficult to learn the right skills to communicate with people with mental illness.

> *I found it difficult to understand the mental illness and communicate with my daughter. (Participant no. 3)*
>
> *I didn't even know what I was dealing with---- I expect information and help, I suppose. I don't know, navigating this thing that we're in. (Participant no. 5)*
>
> *I want information. I'm hungry for information. (Participant no. 20)*
>
> *I was struggling, didn't have the education and the confidence, and the ability to ring around cause it's hard to pick up a phone. (Participant no. 10)*
>
> *You've got to be incredibly careful how you're handling things as well. And that can be quite difficult times, but it's like walking on the glass. You've got to be very careful how you word things at times because that one can take offense. (Participant no. 22)*

3.1.6 Fear of harm by their loved ones

It is not unusual for mental health carers to experience threats or harm from their loved ones with mental illness. In most cases, carers are reluctant to speak about these issues. However, several participants shared experiences where their loved ones physically attacked them.

> *I've had holes in the walls, knives pulled on me, screaming and yelling all over the place. (Participant no. 2)*
>
> *He wouldn't go to the hospital and [the police] took out an AVO on my behalf. (Participant no. 27)*
>
> *She pushed me into the bedroom and wouldn't let me out of the room. I felt very scared and very intimidated, because when she gets into one of her rages, she's very, very strong. (Participant no. 15)*
>
> *He has gone off his medication a few times and when he gets a little bit manic…. Once he pushed me and that frightened me. (Participant no. 20)*
>
> *When she's in a really bad state, I have to just pack up and take off. (Participant no. 24)*

3.1.7 Social isolation

We asked participants about their social life. Many carers expressed feeling lonely during their journey of supporting their loved ones. When asked to rank carers' social life from zero (having no social life) to ten (being extremely social), most carers expressed having limited social activities. Interestingly, this was not related to COVID-19 restrictions. In fact, participants stated COVID-19 restrictions has not impacted their social lives as much, since

their caregiving roles have already limited their social activities. As discussed by participant no. 25:

> *I don't think that much has changed with COVID for us because in the last year our lives went through so much change and with COVID basically it is just the same. (Participant no. 25)*

One reason for social isolation was the stigma around mental health illness. Participants stated the stigma around mental health illness prevents them from socialising with friends and family.

> *Probably that a lot more people don't accept it and it's probably because people don't know. There's a lot of silence about the mental illnesses. No one wants to admit you know they've someone in the family has it. (Participant no. 2)*

> *I had no social network. Like if you talk to friends who, who don't have a person with mental health issues and family, and that, it's just not the same. There is not the empathy or understanding. (Participant no. 4)*

> *I don't think people understand if you have an adult child living with you with a mental illness. I would say I keep to myself a lot in my life. (Participant no. 8)*

Participants also expressed that their caregiving roles restricts them from taking part in social activities.

> *Nothing could help us with our social life because it was so controlled by our daughter. We don't socialize a lot because we could never make plans for anything. [A]s soon as we made plans, she would do something which would make us alter those plans. (Participant no. 15)*

> *We are not having a break because it's still like 24-7. Just not planning ahead. I've been unable to plan an entire thing or kind of go day by day. (Participant no. 17)*

3.1.8 Lack of control over life

Participants discussed how caring for loved ones with mental health impacts their ability to control their lives, plan for their lives and pursue their objectives.

> *It makes you worry about going away. You do want to be close by them. I'm not inviting people over as I would because I feel that it's stressful for him. (Participant no. 8)*

> *Going from crisis to crisis was very common and very exhaustive. I say that I have to be very limited about what I can actually commit to as far as ongoing things. I always try to keep the resources energy-wise and also time-wise optimized. (Participant no. 14)*

> *I want sometimes go away for a weekend or for a day and it depends on counselling stuff. So I often can't go. I try not to get things that I have to pay for. Otherwise I'm out of pocket. (Participant no. 17)*

I would really love to go back to work, but sometimes I just feel I can't get out of bed in the morning 'cause I've got no purpose to. (Participant no.26)

Participants discussed that the lack of control over life and inability to set boundaries in caregiving roles is amplified for parents who care for children with mental illness.

You immediately panic, particularly as a mother and you automatically respond… but what can you do, they are your children. Because particularly as a parent, the first thing you think is, I'm a failure and my child is terrible and everyone's going to be judging me. (Participant no.2)

Being a carer restricted me in doing lot of things. I made decisions not to travel when my marriage broke up. It definitely altered the course of my life…. You're constantly in conflict because basically as a parent you think, well, I have to look after my child, I have to do this and it's not anyone else's responsibility. But when dealing with them at all with mental illness, everything about your concepts and ideas changes. (Participant no. 21)

3.2 Expectations from One Door (ARAFMI Illawarra)

When we asked the carers what were their expectations from ARAFMI, 69% of them expected to receive educational information (see Figure 8). Many carers had attended carers programs such as Family Connections and BPD education and support groups previously. Some carers expected to broaden their social life by meeting people who shared similar experiences and hoped that this would empower them to take more control over their lives.

However, a number of carers program were suspended due to COVID-19. Carers suggested that online education programs, and general information for carers in a mobile application would be helpful.

I think a lot of [carers] don't come to meetings because they don't have time or, the certainly get interrupted 20 times a day by one they're caring for. We're all digital now, everybody has their phone attached to them. So I think its' nice just to be able to sit down and look at the app and see what's happening, and then you're not at a meeting where your phone's going off 50 times… I think people really do want the information. (Participant no.2)

When my daughter's got violent or carried away with her psychosis, I could imagine that all the links for support. Just having hose sources of information [in the mobile] would be useful. Also, having mindfulness recordings that you can put on the phone when things are critical (Participant no.4)

Online information on Carers' rights and responsibilities. And who you can go to, if you feel like you're being brushed aside, would be helpful. (Participant no.10)

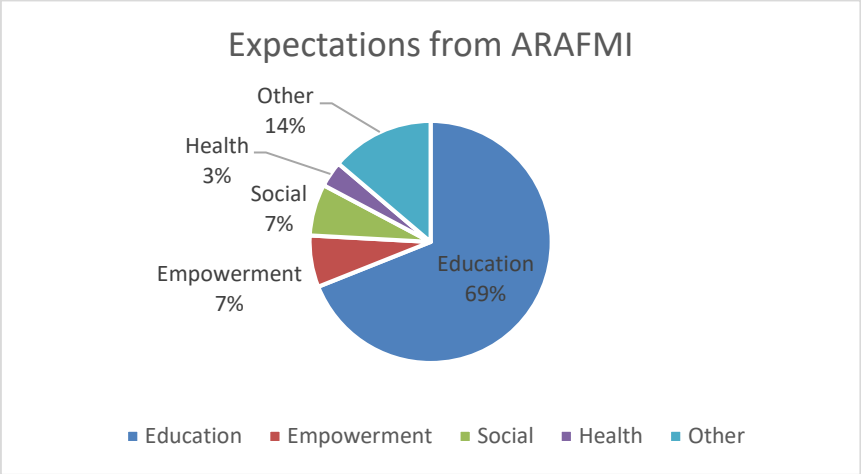

Figure 8 Expectations from ARAFMI

3.3 Outcomes

After identifying the challenges that mental health carers experience in their caregiving roles, we turned our attention to the outcomes of the services delivered by ARAFMI. Participants mostly attended recreational activities such as respite, BPD support group, counselling services, short and long-term educational services, and socialising activities such as coffee dates or walking groups. Participants indicated that these services enabled them to overcome some of the challenges identified earlier. The section discuss the outcomes of ARAFMI services on improving participants' wellbeing in terms of mental health, socialising, safety, and lack of control over their lives.

3.3.1 Improved Mental Health

We asked participants to rank their mental health after attending ARAMFI services from zero (being extremely unhealthy) to ten (feeling extremely healthy). Figure 9 shows carers' mental health rating after accessing ARAFMI services. Over 96% of the participants responded that their mental health had improved after accessing ARAFMI's services.

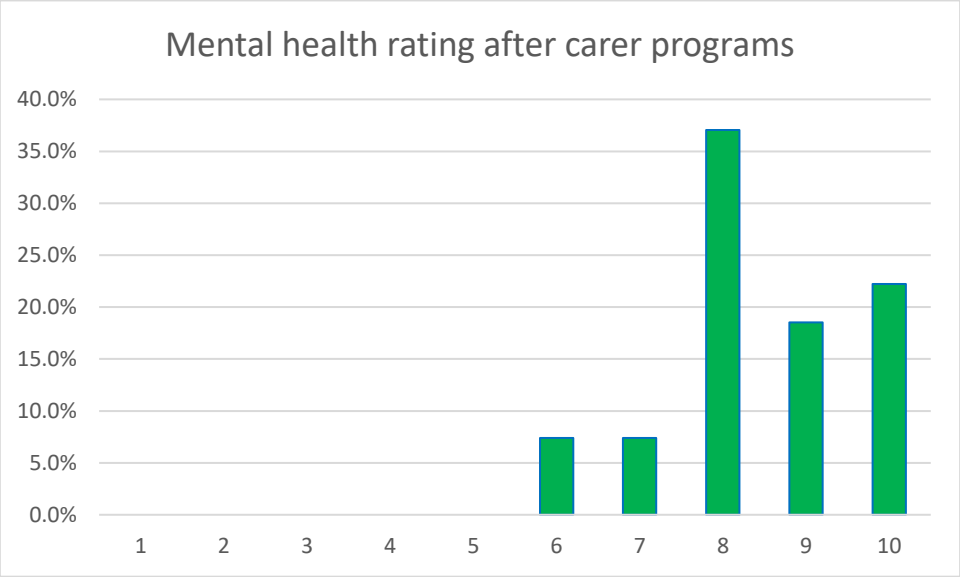

FIGURE 9 Mental health ratings after carer program

Participants discussed that support groups and education programs improved their mental health by enabling them to manage their anxiety and stress.

> *Because we got answers for things, it reduced the agitation and the anxiety. And to know that there are people there that can help you and that you can call if you need to, that reduces your agitation straight away, just knowing that someone understands and can empathize with you. (Participant no. 16).*

> *I learned to cope with my anxieties. Certainly, I'm not as agile as I used to be, both mentally and physically, but I could be a lot worse if it wasn't for ARAFMI. (Participant no. 10)*

Participants indicated that educational courses improved communication skills with their loved ones, which in turn improved the carers' mental health:

> *It taught me things like I need to take time out. I need to find things where I can settle myself down and relax when I get stressed ….[It] gave me tools to work with at home, as well as how I could make my life a bit easier for myself and my husband. (Participant no.25)*

> *It certainly was very useful on the day and some time off afterwards. Yes. I think if you will bring to mind some of the skills just like humming and just being in the moment and reminding yourself of that. (Participant no. 8)*

> *I think in having some confidence in how you approach your daughter or situation it does help you. It does help you mentally. I'm better off doing it this way than the way I used to do it. (Participant no. 4)*

> *The important thing was that we were taught how to look after ourselves, and to help our grandson make life decisions. Not make the decision for him. Basically we learned about my health principle, and coping skills and all that as well. (Participant no. 11)*

Being able to be there and understand and support her, and use skills and communicate to her differently, just made the world a difference. And without those skills, there's no way in the world I would have been able to talk her down from harming herself. And then also being able to recognize I have to call an ambulance. (Participant no. 13)

One of the things that I learned in the course was to change my expectations. And it's a big thing. You'd have to change your unconscious biases and prejudices that you don't even look at half the time. You've to look at your own shadow once in a while and it's very difficult to change. And so I learned that I have to do it to approach it differently. (Participant no. 26)

Participants also expressed that counselling services and support groups educated them on the importance of self-care and setting boundaries, which was important to improve their mental health.

I learned that I needed to look after myself to maintain my ability to look after him…I learned that I needed to set some boundaries and I needed to look after myself so I could continue to support him because it's extremely demanding. (Participant no. 3)

I realized that I do have to worry about myself and looking to caring for me as much as my daughter. (Participant no. 4).

[ARAFMI] helped us a lot to figure out about ourselves and to set boundaries, and then you use these boundaries on everything. (Participant no. 16)

[L]ook after yourself and go for a walk, go to the doctor, the counsellor. I actually did go to see a counsellor a long time ago. (Participant no. 1)

In addition, social programs and support groups improved participants' mental health by enabling them to overcome the loneliness they experienced.

You could offload and talk to other people [who] knew what you were talking about. Friends just can't cope with it. (Participant no. 5)

I was able to spend time with like-minded people who truly understand what you're going through. (Participant no. 2)

[I}t's just knowing that you're not by yourself, that you're not the only one who's experiencing these things. You're not the only one who's exhausted. You're not the only one who needs a time out to recharge. (Participant no. 18)

We didn't realize BPD was such a widespread problem. You think it's just you. You don't realize that there's probably lots of other people going through it. The support from [ARAFMI] and the awareness of it, and meeting the other people that were in the groups and realizing just how bad it was for everybody. It's a relief when you find that out, that it's just not unique to yourself. (Participant no. 15)

I didn't feel so alone. I realised that other people have the same issue. (Participant no. 10)

It was very good to share with people and hear other people's stories to know that you're not alone. (Participant no. 8)

3.3.2 Improved Social life

Another issue raised by our participants was lack of social life. Participants indicated support groups and social activities with people who shared similar challenges improved their social lives.

Those services helped me build a social network and most of my friends are carers. (Participant no. 4)

I've certainly made friends through the various courses I've been to and the groups. And the friendship I've made has been excellent. We exchange phone calls. We go for walks. I found that it's been a good gap in sharing what we're going through rather than imposing that on friends who don't quite understand what it's like to have somebody with a mental condition. (Participant no. 21)

From that retreat, I kept in contact with two of the women. Then I got in touch with the people that went there. So that's sort of a support talking to people that have the same problem, because you're not alone. (Participant no. 1)

I think my social life has improved. When I've gone to [the support groups and workshops]. I've interacted with other carers, which has been really positive. [J]ust maybe talking to other people [who] have got similar experiences. (Participant no. 17)

Participants indicated that connecting with other carers was valuable in terms of learning new skills.

As a carer, I personally found it valuable to be able to learn from other people who are dealing with similar issues. (Participant no. 3)

We weren't taught how to do things [in the support group]. Everyone was open, and we learned from others what can and can't be. That's how it was. People were open, and that's the way to learn. It wasn't like ARAFMI gave us these little points. It's not like a bomb alert. It wasn't an originated point, because at different stages things can happen. We've just learnt different things from everybody else. By the time the session finished, all the questions we were going to ask were answered. Also they encouraged everybody to have a say. (Participant no. 12)

3.3.3 Feeling Empowered

Participants indicated that attending educational sessions and support groups gave them confidence to talk about mental illness and challenges they experience.

> *I've been empowered to talk about mental health and to share my story. ...I've been empowered to recognize and use my skills. (Participant no. 13)*
>
> *After I did the Family Connections course, I was more open to talking about things because you realize that there's a lot of people who are dealing with mental illnesses and you have absolutely no idea. You just think there's not very many people dealing with it. Then you find out that at least 50% of the people that you actually know have got somebody who's suffering or has suffered from a mental illness. I also learnt [that] you have to take time for yourself as well. (Participant no. 6)*
>
> *It empowered me to not have the stigma and have more of a voice in speaking up and talking about it as my journey, sort of separating him and speaking how it was for me going through all of that. (Participant no. 21)*
>
> *In those sessions, everyone is equal. So everyone gets a turn. I never had that before. So now I think they taught me to have a voice. (Participant no. 23)*

Participants also discussed how educational sessions gave them confidence in their caregiving activates.

> *I feel more confident that I don't have to have all the answers. I don't have to solve all problems. (Participant no. 9)*
>
> *We did find that the information that we learned about borderline personality was immensely helpful in helping us cope with his ups and downs. They were able to help us with the pattern where they do not want to tell you the truth about things. That gave me back some strength, some confidence, and to remember to look after myself. (Participant no. 11)*
>
> *It's given me tools to work with, so that it's given me an understanding of the situation and manage the situation better. I'm not so lost or scared of anything I understand what's going on. (Participant no. 24)*

Another outcome of the educational sessions was to motivate carers to value themselves and take steps to make changes in their lives.

> *At ARAFMI, it's about looking after the carers, and arming us with the skills to ask for help, or to be assertive, and where to go to get help for that person..... we had to understand what BPD was and accept it. The acceptance of that and knowing that there's no way to fix it, you can't fix what a person is, and that's fine. It eases the pressure to know it's not our fault, and that we must look after ourselves. (Participant no. 12)*

I'm pulling my hair out, what do I do? How do I fix them? And until you learn that you don't, then you go, Oh, I was never going to fix them. That's the professional's job. I just have to try and function. (Participant no. 2)

I think they make you feel like you are useful as a person, rather than saying you are just somebody that looks after someone with a mental illness. (Participant no. 17)

I am now more aware of not taking responsibility for the other person's behaviour and just doing what you can. (Participant no. 10)

3.3.4 Increased Feelings of Safety

Participants shared that one outcome of educational sessions was to develop skills to identify the sings of crisis, which in turn empowered them to deescalate situations and feel safe in their caregiving roles.

Now I know the signs when he's unwell and I know how to be around him. (Participant no. 23)

I learned to just be very calm and quiet and not aggravate the situation at all and also how to deal with his delusions when they happen. So that has been really helpful actually. (Participant no. 25)

We know how not to inflame the situation and that we can close the door and walk out. (Participant no. 11)

With the police visit, I spoke to [the police] and he said to me, "You're leaving it go too long…You need to either be calling us or getting him out of the house before it gets to that level". So, I have been working on that, as soon as it escalates, I need to go. And sometimes it works. (Participant no. 2)

Participants also stated the Crisis Manual developed by ARAFMI is significantly helpful in managing the crisis.

[ARAFMI] has a guide plan and I would follow that plan, which is I would go to my sister-in-law. And then I would get in contact with services that I'm aware of as well. (Participant no. 13)

We get all information, all phone numbers. We know exactly, who you can call and the way to go. (Participant no. 21)

They have a lot of information when I go there. A lot of information, which is really positive. And I have a little book that I put out, which has all the numbers and everything. (Participant no. 17)

3.4 Summary

This section summarises the responses to interviews conducted by the research team with 27 mental health carers. Our findings indicate that there is not sufficient governmental support available for mental health carers in the Illawarra region, and carers significantly rely on services delivered by community organisations. Although carers are the ones who provide the most support for their loved ones with mental illnesses, they are often excluded from discussions with health professionals. We also found there is an extensive financial strain associated with caring for someone with mental illness. Our findings show that this financial burden hinders carers' ability to plan for their life, socialise, and has an impact carers' mental health. The stigma around mental illness and lack of sympathy and understanding from friends leads to carers' social isolation. The findings further revealed that carers often experience harm from their loved ones with mental illness, and carers are not able to control their lives and pursue their objectives. One important finding of this project is that this cohort of mental health carers have developed mental illness themselves. In particular, the findings show that carers' lack of control over their lives due to caring for someone with mental illness, social isolation, lack of understanding of mental illness, a lack of communication skills with their loved ones with mental illness, as well as the lack of education on the importance of self-care further complicates the circumstances of these people.

Our findings reveal that carers heavily rely on educational sessions delivered by a community organisation. This project found that services delivered by community organisations can improve the wellbeing of mental health carers. Short term and long term educational sessions provide an understanding of mental illness, develop communication skills, and build coping skills and resilience. This in turn has positively impacted carers' own mental health. Within this cohort, socialising with like-minded people and education from peers has a significant impact on carers' mental health and overall wellbeing. Socialising with people who shared the same experience not only enabled them to overcome the feeling of loneliness they often experience, but also fostered peer learning. Moreover, educational sessions empowered carers to gain confidence in their caregiving roles, set boundaries, and gain more control over their lives. In addition, services that taught carers to identify the signs of crisis, de-escalate the situation and manage the crisis, as well as developing a crisis plan improved carers' feeling of safety In their caregiving roles.

While educational services are fundamental in improving the wellbeing of mental health carers, unfortunately some carers, particularly those who were working full time, or carers whose physical health prohibited them from accessing these services, could not fully benefit from them. In addition, during COVID-19 restrictions, all services were on halt. As such, while, during COVID-19 restrictions, ARAFMI introduced phone counselling services, it is crucial to for community organisations such as One Door to deliver online educational services.

In the section that follows we demonstrate the impact pathways to develop the mental health carers wellbeing framework for community organisations.

Section Four: Discussion

Section 3 described the challenges experienced by mental health carers and the outcome domains significant to mental health carers' wellbeing. In this section, we draw on the evidence gathered through our interviews to articulate the impact pathways to develop the mental health carers wellbeing framework. The outcomes framework for mental health carers' wellbeing consists of the linkage between each outcome domain objectives and the pathways to achieve those objectives.

4.1 Health Domain

Linkage between education and health

Our findings demonstrate that educational courses delivered by One Door positively improve carer's mental health. Figure 10 shows the education to mental health pathway.

- Short term and long term educational courses provide an understanding of mental illness. This will lead to improved carers' communication skills with their loved ones. Having a better understanding of mental illness and improved communication skills reduces disagreements and tension, which in turn improves carers' mental health.
- Educating carers on the importance of self-care and teaching skills to manage anxiety improves carers' mental health.

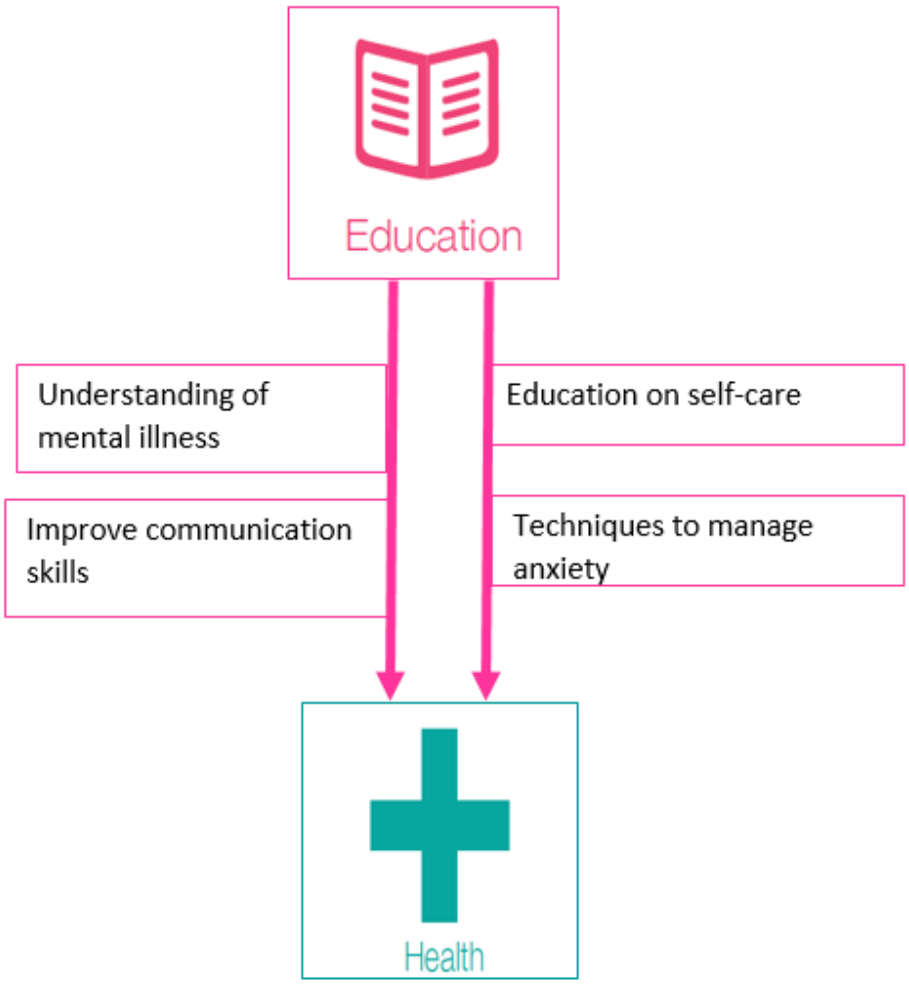

FIGURE 10 Linkage between education and health

Linkage between empowerment and mental health

Figure 11 illustrates the pathway from empowerment to mental health.

- Having control over life improves carers' mental health.

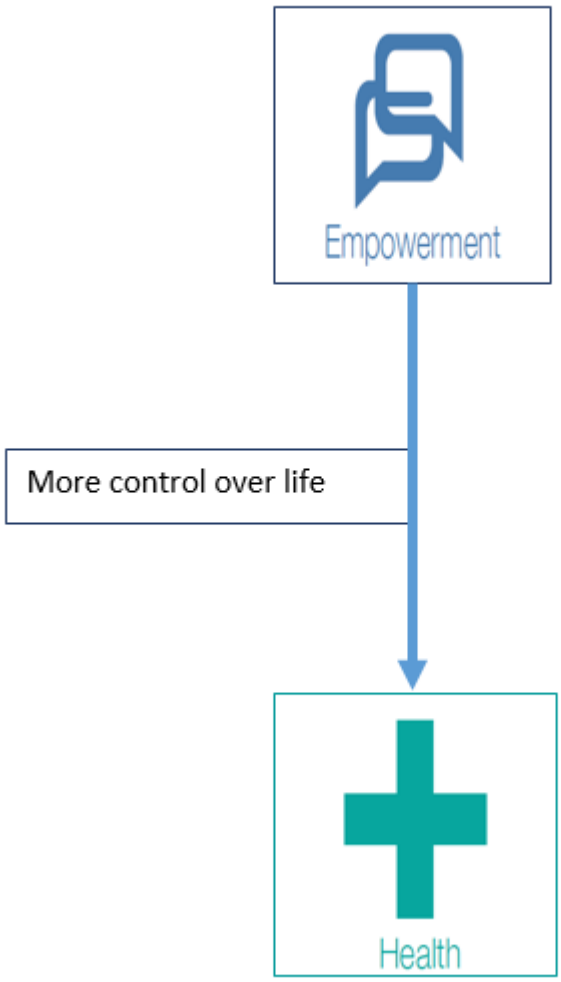

FIGURE 11 Linkage between empowerment and mental health

Linkage between social and health

Figure 12 illustrates the social and community pathway to improve carers' mental health.

- Peer learning educational sessions and socialising with like-minded people enabled carers to recognise the extent of mental health issues and helped them overcome the feeling of loneliness, which in turn had positive impacts on their mental health.

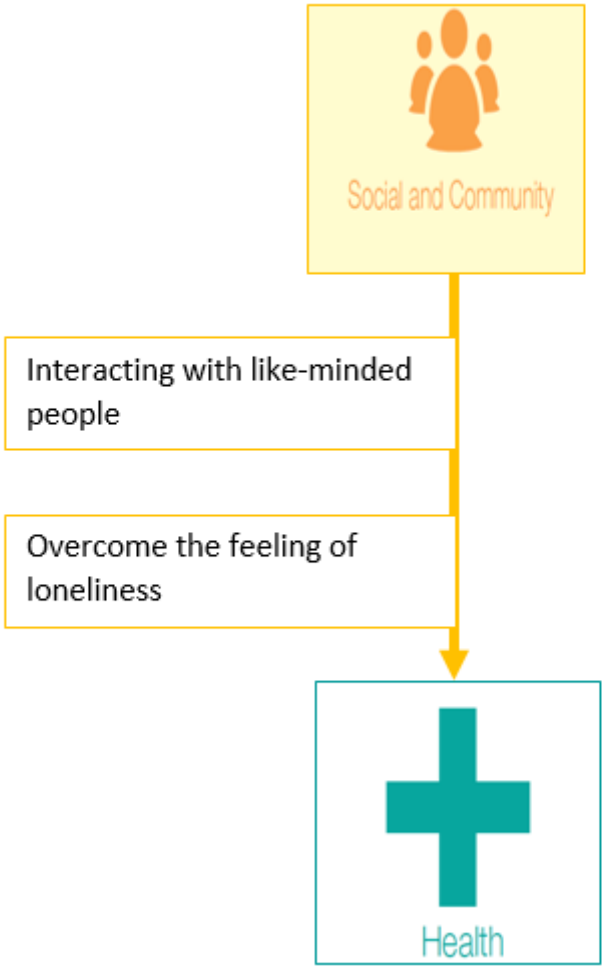

FIGURE 12 Linkage between social and mental health

4.2 Social Domain

Figure 13 shows the pathway from empowerment and health to improve social life.

- Carers who have more control over their lives can attend social activities, this leads to being able to create a social network of carers and improves carers' social lives.
- Carers who are physically healthy can attend a variety of social activities, engage with other carers and have a better social life.

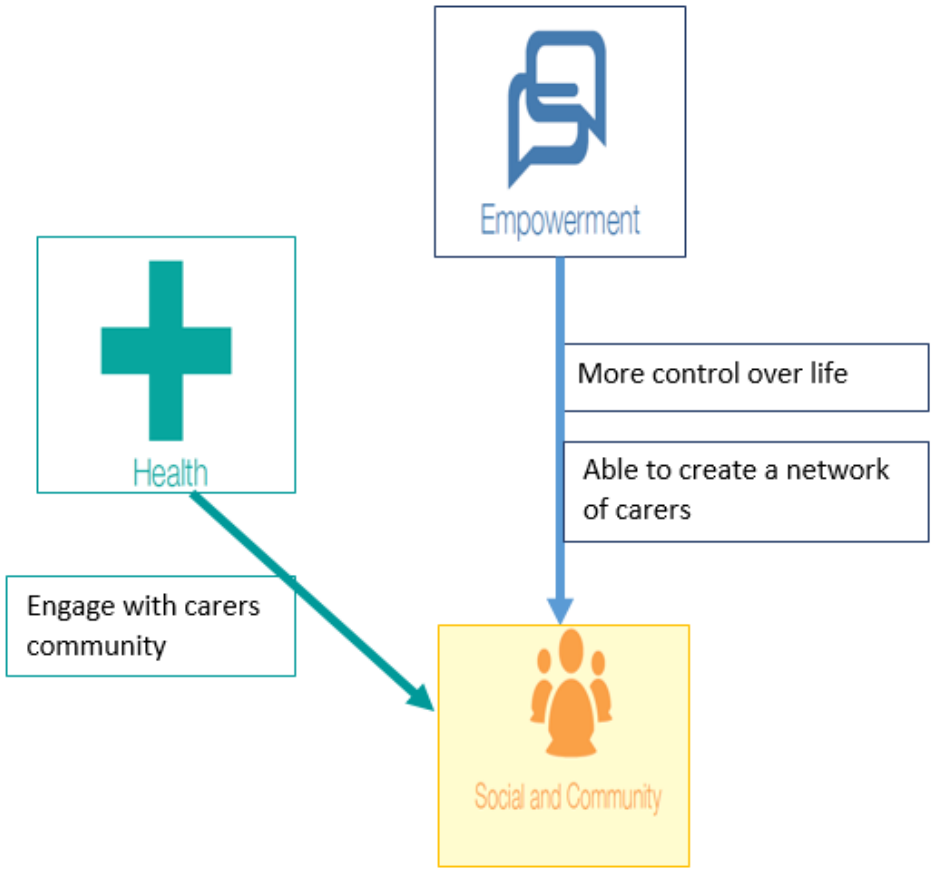

FIGURE 13 Pathway from empowerment and health to improve social life

4.3 Education Domain

Figure 14 shows the pathway from social and community to education.

- Socialising with other carers who are experiencing the same issues improves understanding of mental illness and enables carers to learn new skills.

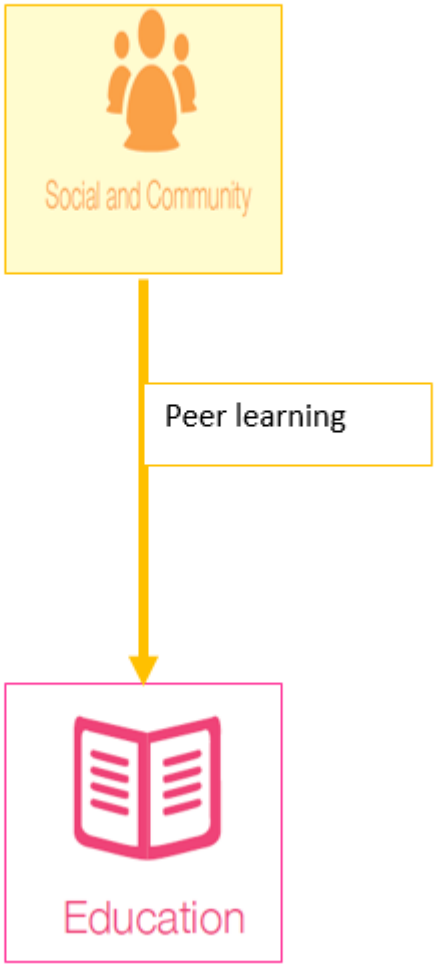

FIGURE 14 Pathway from social and community to education

4.4 Empowerment Domain

Figure 15 illustrates the pathway from education to empowerment.

- Educational sessions enable carers to overcome the stigma attached to mental health and empowers them to speak publically about mental health issues.
- Educational sessions empower carers with confidence in their caregiving roles.
- Educational sessions motivate carers to set boundaries when caring for their loved ones. This empowers them to have more control over their lives.

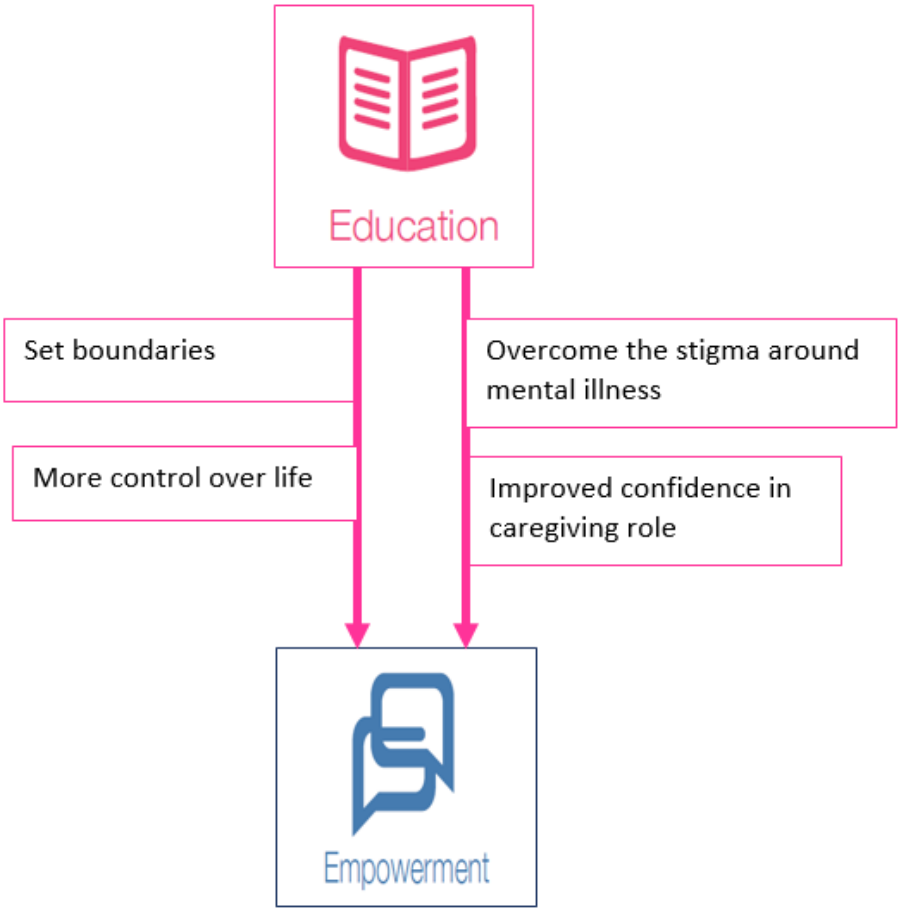

FIGURE 15 Pathway from education to empowerment

4.5 Safety Domain

Figure 16 shows the pathway from education to safety

- Educational sessions that teach carers to identify the signs of crisis and to develop skills to de-escalate the crisis improves carers' safety
- Educational sessions also improve carers' safety by teaching them to develop a plan for managing crises.

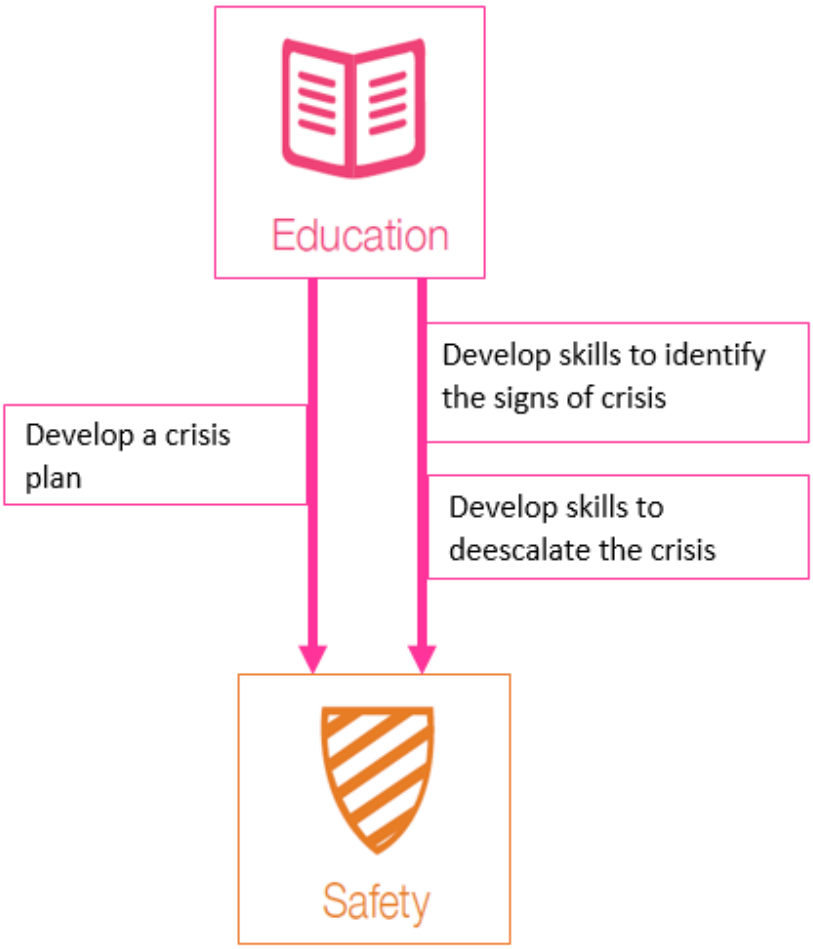

FIGURE 16 Pathway from education to safety

4.6 Outcome model for mental health carers' wellbeing

Drawing on the impact pathways exhibited in Section five, we developed an outcomes framework for improving mental health carers' wellbeing by community organisations. As mentioned in Section 3.3, this framework incorporates outcome domains that community organisations must prioritise when developing services for mental health carers. Figure 17 demonstrates educational services are the cornerstone of improving mental health carers' wellbeing through community organisations.

It is important to mention that while our findings identified that financial strains associated with caregiving negatively impacts carers' wellbeing, the evidence gathered by our interviews shows carers do not expect financial support from community organisations. However, as mentioned in our recommendations (Section five), community organisations could advocate to improve governmental financial supports for carers. Community organisations could also assist carers in navigating systems when applying for financial support. Other non-profit organisations that provide financial services, such as the St Vincent de Paul Society and the Salvation Army, could incorporate the Economic Domain and Home Domain when developing a wellbeing framework.

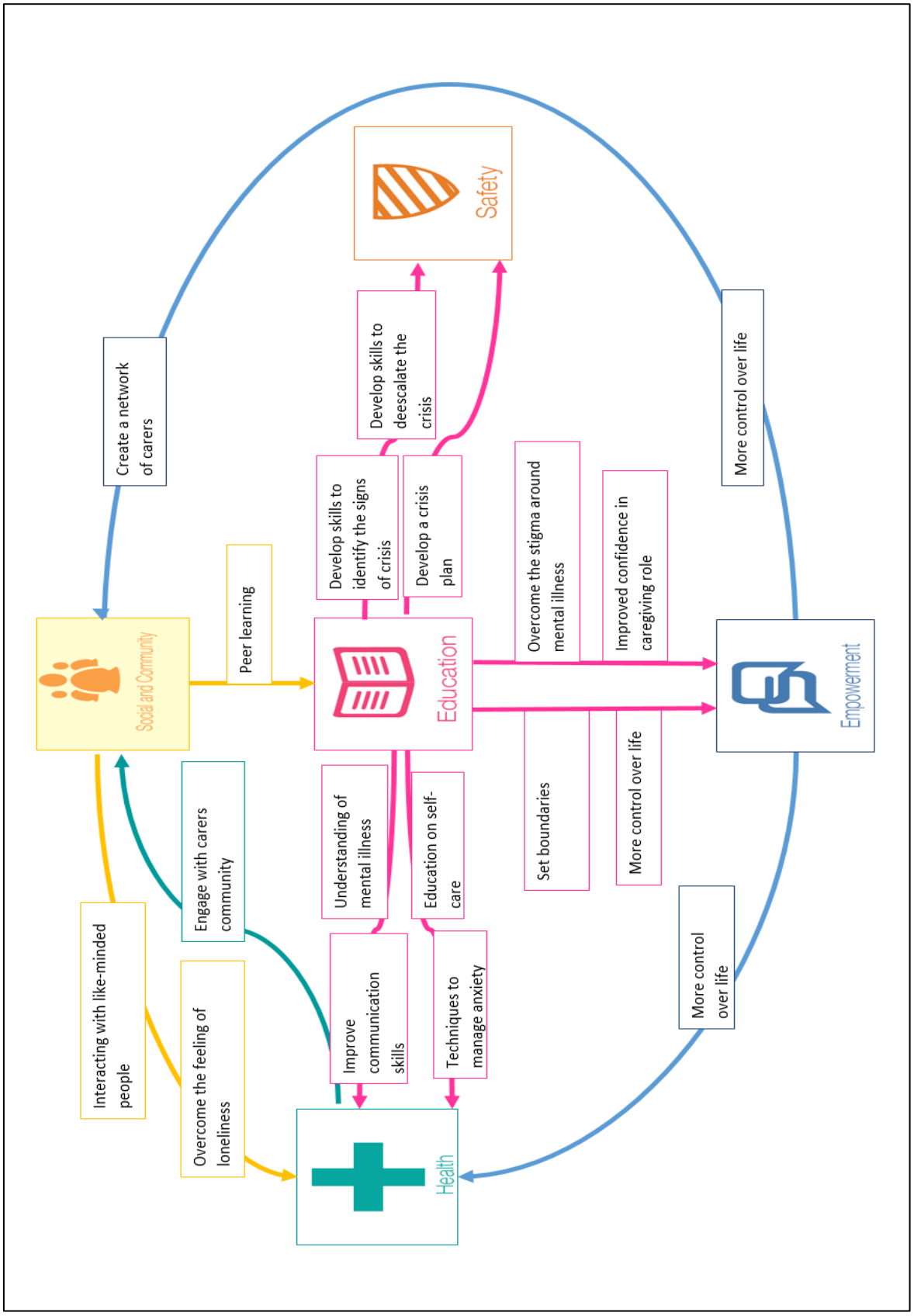

FIGURE 17 Outcome model for mental health carers wellbeing

Section Five: Recommendations

In response to the experiences of our interviewees, we propose the following recommendations.

5.1 Increase support for carers

More funding is required for non-profit organisations to be able to deliver flexible support programs for working carers to attend. Services such as respite care are needed to provide relief from the demanding carer role.

5.2 Mental health carers advocates

The financial burden of caregiving negatively impacts mental health carers' wellbeing. They have limited access to governmental support payments such as carers allowances, particularly if their loved ones are not deemed eligible for the Disability Support Pension or the NDIS. Community organisations such as One Door could advocate for mental health carers to be recognised as carers and access governmental payments and funding as well as assisting carers to navigate the system when applying for the NDIS.

5.3 Organise more support groups and counselling services

Emotional stresses for carers are widespread and often hidden. These stresses have a negative impact on carers' wellbeing. Support groups and counselling services could provide a venue for carers to vent and would provide emotional support. Community organisations can be more inclusive by organising weekend sessions and after hours programs.

5.4 Provide ongoing information sessions and educational programs

Seminars and workshops for carers targeting different types of mental illness would help improve their understanding of the illness and their ability to communicate with their loved ones. This in turn will empower carers to have more control over their lives.

5.5 Develop a mobile phone application tailored for mental health carers

Information for carers is usually segregated and often hard to find. A mobile phone application will provide a one-stop shop for carers to access important and timely information that addresses the carer's individual needs at the time when they need it. For example, the application would contain hotline numbers, carers' support facilities, recorded sessions and upcoming events for carers. The application may also contain a section that can help carers plan and prepare in advance for a crisis.

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