4 April 2019

**Mental Health Carers ARAFMI Illawarra-Submission to the Productivity Commission Inquiry ‘The Social and Economic Benefits of Improving Mental Health’**

Mental Health Carers ARAFMI Illawarra is a non-for-profit organisation which has been providing support to carers and families in the Illawarra region for over 35 years. We provide carer counselling, telephone support, carer advocacy, support groups and empowerment and relationship programs for carers.

ARAFMI Programs are quite unique to carers as we provide empowerment to carers through educational and peer groups. Most of these groups are run out of general business hours. We feel this is beneficial to working carers. These groups are facilitated by experienced carer volunteers.

Our organisation is always seeking more funds, not only to support and enhance our current support programs but to also introduce new and sustainable supports to carers and families.

Our meaningful partnerships with the University of Wollongong and TAFE Illawarra have brought many opportunities and initiatives to assist our support services.

One initiative has been the implementation of the Carer Check Up. “The Carer Check Up” is a brief structured intervention that aims to assist carers navigate the various support services on offer through the assessment and provision of individualised feedback.

What a carer can expect after completing the Carer Check Up is an increased awareness about his/her current circumstances and impact it is having on him/her, increased knowledge about the ways he/she can support themselves and their loved one, and a clear understanding of what support options are on offer that specifically match to his/her individual needs.

Our organisation is also a recognized host for student placements with TAFE Illawarra and University of Wollongong. Students who choose to be placed with our service are students studying Diploma and Cert IV Community Services, Mental Health and Peer Work. Students from UOW are studying Social Work and we periodically host Psychology students who are beneficial in working with carers and their families.

Over the last 12 months ARAFMI researched and developed a Crisis Manual for carers and families. This resource is to assist and support carers when faced with an immediate crisis.

There is also the possibility for this resource to reach the wider community through our local hospital Emergency Department and Mental Health Units. There is also the potential to roll this resource out to other regional areas within NSW and throughout Australia with region-specific resources.
The Crisis Manual includes:

- What to do in a crisis
- Who to call
- What to expect when dealing with emergency services
- What happens when you present to ED
- How can carers be more involved
- Admissions and the rights of carers
- Financial and legal considerations
- Terminology carers may come across in the mental health service or hospital setting
- Other post-crisis resources.

Carers provide us with feedback regularly through our support groups and through face-to-face counselling. Many times we have identified issues through advocating for carers also.

General Gaps for carers that have been identified quite regularly have been:

- Carers feel unsupported and overwhelmed when presenting to ED or general mental health services
- Carers don’t know what they want or need or where to go to find out what they may be needing in times of stress
- Carers don’t feel heard and listened to
- Carers are feeling that not one-size-fits-all boxes, everyone may have different stories of why they need mental health services and supports, or what brought them to ED or to the service.
- Carers are unsure how to support loved ones on discharge, not being given enough information or support on discharge
- Carers are still feeling their loved one is released too soon
- Carers are not receiving adequate referrals to community services for follow-up or support and/or choices in the support that could be offered to them
- They feel health and community organisations are not working together for the best outcome of the family.
- Health vs justice system: people falling into the justice system because of mental health issues. This has an impact on the community and increases stigma within the mental health community.

**FUNDING**

Funding seems to be becoming more competitive, and sadly, funding for carers and families seem to be a hit and miss. Recently we applied for a small grant through the Community Grants Hub for training for carers and volunteers around suicide intervention, mental health first aid and occasional counselling training. We missed out on this funding. This training would have assisted our community organisation with volunteers being adequately trained to be able to provide immediate advice and peer support to other carers and families on a voluntary basis.

We feel that we are at a disadvantage to receive extra funding for our service that would enhance our programs and assist with our quality improvement and support systems for carers. We are encouraged and
congratulated on utilising volunteers but then at a disadvantage when applying for grants to train our volunteers.

**EMERGENCY DEPARTMENT PRESENTATIONS AND MORE EDUCATION AND TRAINING TO FOR NON MENTAL HEALTH STAFF**

We feel the Emergency Department is not the appropriate department for people in distress to be presenting to. There could be a more suitable and adequate place or department for people to present to. This in turn would take pressures off the ED waiting times also. We believe that the reason people are expected to present to ED is to be triaged by medical clinicians before mental health clinicians see patients. We feel the stress on the system along with families and the person in distress could be alleviated by presenting to a specialised department and a medical expert could consult with the patient through this department.

We feel more training is needed for staff to treat and assess people presenting to ED with BPD symptoms and suicidality. Carers often express the frustration they experience when presenting to ED with a child or a loved one who has self-harmed and / or who have suicidal thoughts. It has been stated that people who experience traits of BPD do not fit into the hospital system.

Carers feel that staff that do not have appropriate training on certain mental health conditions such as Borderline Personality Disorder often can be judgmental and lack empathy for that person suffering, and their carers. Most often carers feel they are blamed and looked upon as the ones that are not mentally stable or are to blame.

We also feel that ongoing suicide prevention training should be mandatory, as is CPR and general first aid in many, if not all, workplaces. More carer and family friendly training for mental health clinicians, non-mental health and hospital staff and other ongoing professional development on mental health training is necessary.

**CRISIS AND ADVICE**

The current NSW Mental Health line number has had a mixed response from carers and families. Some carers have reported that they do not get any advice on where they can go or what to do in crisis except to call police. Triple zero (000) needs to be also highlighted within the media along with other helpful support numbers. “If you are in immediate crisis and need assistance call 000”

Although this advice can often be a worthy option in a crisis but sometimes carers are looking for alternative solutions that they can opt for especially if the person is wanting help but is not wanting to present to ED. First and ongoing experiences can have a lasting effect on families and the person they are caring for who may have presented to ED previously and had negative experiences or outcomes.

“A recent story from a carer was that she presented to ED with her 18-year-old daughter who was very distressed. She was turned away from ED and not even 24 hours later her daughter suicided. Sadly this story is becoming a common mental health story from families.”
MENTAL HEALTH SERVICES SHOULD BE WORKING MORE CLOSELY WITH COMMUNITY SERVICES WITHIN THE COMMUNITY

It has been recognized that the NSW Mental Health line number or local mental health services number are not advertised widely enough for people or families facing crisis or suicidality. These numbers are the main numbers linked to a mental health crisis.

Although Lifeline is critical for people also in crisis, other organisations are invaluable for people looking for mental health resources in general and are extremely helpful in the pre and post crisis situations.

There seems to be a health vs justice intervention when it comes to assisting people within the community. Emergency services now can schedule patients (in NSW) but there are instances of hospitals soon releasing patients back into the community as quick as they are presenting. Which in turn puts pressure straight back onto the emergency services, most often than not the patient falls into the justice system.

It is often quite difficult in getting "meaningful access" to the local mental health service both in terms of the Directorate and staff ‘on the ground.’

More mental health nurses, counsellors and social workers could be employed by community services and GP practices. If services within the community had the ability and funding to provide more mental health support as needed this could address gaps of crisis support and free up ED resources and waiting times.

More community mental health workers working within the community to provide home visits: a previous service in our region called the Mobile Crisis Team was abolished years ago due to conflicting reasons. One reason was around work health and safety.

Many suggestions to overcome these risks have been identified over time. One previous suggestion from a former local mental health manager was the employment of security personnel to work in conjunction with clinical staff in the community rather than two clinical staff. This change in staffing would have allowed mental health clinicians to continue to work after hours with those in crisis, in a manner, which was conducive to ensuring safety and minimising risk. The suggestion received little support from senior management and staff are now limited to working business hours only.

Today it’s currently a business hours model with an extended hours phone service. Whatever the outcome, more needs to be done to ensure community staff working in extended hours teams are available for face-to-face consultation in the community after 5pm, not providing a telephone counselling service which it could be argued already exists with Lifeline and other similar services.

MEDICARE

The cost of trained and experienced psychologists is a huge barrier for people seeking treatment. Treatment for Illnesses such as PTSD and Borderline Personality Disorder require ongoing and extensive therapy and the allocated sessions that are currently offered through a mental health care plan is just not enough.
More affordable psychological sessions with experienced therapists are needed. This also relates to more affordable consultations with psychiatrists. A large percentage of the community cannot afford treatment. Currently we have a maximum of 10 sessions on a mental health care plan for a specialized psychologist or counsellor. This does not even equate to one session per month.

Complex disorders such as PTSD, BPD and/or crisis intervention need to be able to have access on a more regular basis and whilst in crisis this may be weekly until the person is more stable. This cost is a huge barrier for people opting out of treatment due to their financial situation or the gap for treatment is draining their funds.

These illnesses have complex and unpredictable symptoms and often need to be addressed by a trained professional, sometimes as soon as possible. If more sessions were allocated for complex diagnosis, this would allow people to access emergency therapy or care more often instead of presenting to ED or having to wait for their next month’s session, for which some therapists allocate only 50 minutes.

The cost of the gap for highly trained professionals can also be another barrier, with people cancelling their sessions due to lack of finances available for ongoing sessions. People are then looked upon as treatment resistant and/or put in the too hard basket.

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On Behalf of the Management Committee