Senate Community Affairs References Committee Inquiry

Accessibility and quality of mental health services in rural and remote Australia

Submission by: Roses in the Ocean

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Introduction

The Fifth National Mental Health and Suicide Prevention Plan acknowledges the importance of lived experience in two contexts:

People with a lived experience of mental illness are a central part of effectively tackling stigma and discrimination (page 1)

The mental health workforce is in need of growth and development. There is a looming shortage of mental health nurses and limited capacity for effective care of low-prevalence mental disorders in the primary care sector. Peer workers, or workers with a lived experience of mental health, play an important role in building recovery-oriented approaches to care, providing meaningful support to people and modelling positive outcomes from service experiences. However, the peer workforce is sporadically utilised and poorly supported (Page 2)

This submission will demonstrate that people with lived experience of suicide can contribute significantly and it will argue that with appropriate support and resourcing, they can play a much greater role in reducing suicide and its impact across Australia. They can and must be seen as key players in system reform at all levels.

About Roses in the Ocean

Founded on, and operating through the lens of lived experience of suicide, Roses in the Ocean is a lead organisation for lived experience of suicide in Australia. The Commonwealth Government has recently recognised our leadership role with funding through its Suicide Prevention Leadership and Support Program.

Roses in the Ocean exists to save lives and reduce emotional pain.

We do this by informing, influencing and enhancing suicide prevention through lived experience and supporting organisations to effectively and meaningfully engage lived experience expertise.

We focus on …

- providing critical lived experience resources and expertise
- building a trained and supported Lived Experience “Workforce”
- facilitating their meaningful involvement in suicide prevention activities
- leading the evolution of engaging lived experience
- developing the skills of a Peer “Workforce” in the context of suicide

We play a significant multi sectorial advisory and consulting role with regard to lived experience engagement; work closely with Primary Health Networks (PHN) across Australia, Commonwealth Trial Sites and Victorian Place Based trials, and are developing a Lived Experience workforce across Australia. We are the lived experience partner to Black Dog Institute’s LifeSpan project. Additionally, we have established partnerships and collaborative initiatives with numerous organisations within the suicide prevention, mental health and workplace wellbeing sectors.

Recognising the importance of evidence-based practice, Roses in the Ocean programs are currently being evaluated through leading Australian Universities and Research Institutions to determine the impact of our lived experience activity, inform continuous improvement and contribute to the international evidence base.
Scope of our Submission

This submission focuses on the potential for improving responses to suicide prevention through increased acknowledgement of the important role that can be played by people with lived experience of suicide. In doing so, it will make specific reference to suicide prevention through lived experience within the following elements of the Terms of Reference:

(c) the nature of the mental health workforce;
(d) the challenges of delivering mental health services in the regions;
(e) attitudes towards mental health services;

It will provide insight from people with lived experience perspectives as well as from the perspective of a lived experience organisation delivering services in rural and remote Australia.

Understanding lived experience of suicide

The Fifth National Mental Health and Suicide Prevention Plan defines Lived experience of suicide as:

- People who think about suicide, people who have attempted suicide, people who care for someone with suicidal behaviour, people who are bereaved by suicide, and people who are impacted by suicide in some other way, such as a workplace incident

Roses in the Ocean has adopted the following definition:

…having experienced suicidal thoughts, survived a suicide attempt, cared for someone through a suicidal crisis, or been bereaved by suicide.

In defining lived experience of suicide in this way, we seek to stress the importance of differentiating between those many people who may have some colleagues and acquaintances who have died by suicide and those who live with the impact of suicide that affects them in an on-going way. This definition has been developed by people with a lived experience of suicide over a number of years.

While not wanting to trivialise the impact of any suicide on anyone, Roses in the Ocean takes the position that ‘some other way’ does not do full justice to the complex grief and trauma experienced by people with close emotional ties to the person who has attempted to take their own life, or died by suicide, for whom suicide will have a profound and long-lasting impact on their lives.

Approximately 2,795 Australians die by suicide each year. Many more people attempt suicide. For instance, from 2008 to 2009, there were 26,935 cases of hospitalised care due to self-harm. It is important to recognise, however, not all people who are hospitalised due to self-harm may have intended to die by suicide and similarly not all people who attempt to take their own lives are hospitalised. Further research suggests that for every death by suicide, approximately six people (a total of 16,770 a year) are bereaved.

Specific issues

(c) Nature of the mental health workforce

While many people who contemplate or attempt suicide have a mental illness, it is important to acknowledge that a report from the Australian Institute for Suicide Research and Prevention (AISRAP), Griffith University, stated that:

An association between suicide and psychiatric illness was again found, with almost half the number who suicided having a recorded psychiatric illness. However, about the same number had a physical illness, indicating that increased vigilance is warranted not just for those with psychiatric illness. About 30% of suicides had a previous record of a suicide attempt. More assertive follow-up of suicide attempts, which has been trialled with some success in some European centres, is suggested by this result.

Research tells us that in addition to mental illness, a number of other contextual social issues contribute to suicidality. “Tipping” points for attempted suicide have been identified including for instance relationship
separations or debilitating illness. Only those who have reached that point of desperation can provide the depth of understanding and connection that is needed to increase our understanding and capacity to reach out and provide the services that people in crisis actually need.

To address this gap in service provision, Roses in the Ocean is developing a Lived Experience (of suicide) workforce (Lived Experience Collective) across Australia who are actively involved in suicide prevention activities in their local and regional communities. Our National Mentoring Program provides an additional layer of support as these people become engaged with their communities. They are engaged in a wide range of roles including but not limited to:

- Lived Experience Advisory / Reference Groups
- Co-facilitating community forums
- Co-designing training programs and new services (e.g., Lifeline Text4Good service)
- Facilitating suicide prevention awareness workshops
- Participating in research projects
- Hosting events
- Public speaking engagements to raise awareness
- Peer support in the suicide context
- Informing suicide prevention action plans
- Lived Experience Mentors

People with lived experience bring unique and diverse perspectives to suicide prevention activity and service provision. They identify and articulate the impact of what is occurring on the ground in communities all over Australia. They offer insight into what services are desperately needed, what works, what doesn’t, and what people at risk of suicide, or supporting a suicidal loved one, or family members reeling from the loss of a loved one through suicide, actually need to help them.

In most cases, people with lived experience are providing all of the above expertise as unpaid, passionate and driven community members.

Our focus on developing a confident, trained and supported lived experience workforce has seen an increase of the Lived Experience Collective by in excess of 150 people in the first 4 months of 2018 alone.

Through our close working relationships with PHN’s and suicide prevention service organisations, and daily interaction with lived experience people in communities all over the country, a pressing need has become very apparent.

We are consistently being looked to as the organisation to facilitate the connection of various lived experience groups that we have trained, and other community suicide prevention networks that have organically grown over the years. Furthermore, we are being asked by PHN’s to assist in connecting lived experience people with local and regional service providers and organisations, such that this valuable resource can be utilised to its fullest potential.

We believe two key outcomes will be achieved when we are able to offer this State based coordination role:

- strengthened connections between lived experience groups, suicide prevention networks, PHN’s, service providers and other organisations.
- Identification of strategic issues through effective relationships and networks with local service providers and thereby the provision of informed system advocacy and advice at a state and national level.

Australian communities everywhere are desperately calling out for improved services, and alternatives to the highly medicalised model currently available.

In line with priorities identified in the Fifth National Mental Health and Suicide Prevention Plan, Roses in the Ocean recommends investment in consistent and timely care, and assertive follow up, for those who have attempted suicide or are at risk of suicide.
It is time to acknowledge that the health system fails to meet the needs of thousands of individuals in suicidal crisis and that health systems reform will take significant time. We cannot continue telling people to seek help while knowing much of the support available through the health system is under stress, difficult to access, of highly variable quality, and frequently inappropriate for recovery from suicide crisis.

We hear a consistent message from people who have lived through suicidal crisis that non-clinical environments and services staffed with a combination of peers and community support workers, where they feel safe, supported and genuinely understood, would best promote recovery.

In order to provide these much-needed non-clinical alternatives Australia requires a Suicide Prevention Peer Support workforce made up of people with a lived experience of suicide with specialist training to provide peer support in the suicide context. The best peer support workers to support a person in suicidal crisis is a person who has themselves experienced a suicidal crisis. The best person to support someone bereaved through suicide, is a person who themselves lost a loved one through suicide.

This Suicide Prevention Peer Support Workforce (a speciality workforce within the broader Lived Experience of Suicide workforce) needs careful recruitment, quality and specialised training, robust support structures and a coordination body. Due to the nature of supporting people in the suicide context, frequent rotation of peers is required to manage exposure to highly emotional, stressful and potentially triggering situations. This needs to be built into the design of this peer workforce.

(d) Challenges of delivering mental health services in the regions

Much of our work is in regional and rural areas throughout Australia.

There are the obvious challenges relating to isolation, distances to travel, varying access to online support/ internet access and availability of services. In addition to these practical challenges are the barriers caused through community ignorance, stigma—fear, prejudice and discrimination—all of which lead to a reluctance to seek help in many instances. We hear that it is significantly more difficult for men in regional and rural areas to admit they are not coping and require assistance. We are told of situations where communities have shunned anyone who does speak up, and of women who suffer traumatising marital breakdown and domestic violence in silence for fear of being ostracised by the small local community, which has led to their suicidality. In the event of a suicide within a family, we hear of whole families feeling the effects of community stigma, which in turn is detrimental to the wellbeing of the family.

We often hear frustration and anger regarding disconnected service providers and lack of continuity of care from mental health professionals due to regional hospitals being treated as training hospitals with transient medical staff. Lengthy wait times to see a mental health professional are frequently raised as significant concerns in regional and rural communities. People describe how people in suicidal crisis are forced to sit in Emergency Departments with people on ICE and other drugs, and with people with all sorts of ailments—forced to remain in a chaotic environment when they themselves are in crisis. Every day the trauma of suicidal crisis is exacerbated by stigmatising, ineffective care in emergency departments around the country.

As an organisation, we are presented with challenges when we are requested to deliver our lived experience training in rural and remote regions.

- People with lived experience of suicide often come to our programs having never spoken about their experience. When there are few programs, people are required to travel and stay away from home and local support structures to attend training. This exacerbates feelings of anxiety.

- There are also issues relating to the sustainability of a lived experience workforce due to the lower numbers of trained people with a lived experience. Often the regions find themselves utilising the same ‘voices’ which can be detrimental to the lived experience person, and limits the perspectives contributing to suicide prevention activity.
(e) Attitudes towards mental health services

- The ED is the last place I want to go to when I’m feeling suicidal
- I’d rather take my chances feeling unsafe at home than go through the trauma of ED
- They won’t follow my plan. I try to follow it like we agreed and then the mental health unit doesn’t adhere to it and I still spend hours locked in a room in ED
- I’m just going to say what they want to hear so I can get out of here.
- There was no one to help us navigate what happened after we lost our son to suicide
- GP’s just seem to want to write a script and get you out of their office as soon as possible”
- It’s so hard to find where to get help”
- We had no idea how to support my brother after he made an attempt and was released into our care 10 hours later"
- It can take 6 weeks to even see a psychologist
- Our doctors are always changing (our hospital is a training hospital) – they come, do their time, and head back to the city
- “where do you go to get help? – there’s nothing here! And it’s so hard to find information”

Roses in the Ocean co-chairs the 2016-19 Ministerial Taskforce on Suicide Prevention in Health in Queensland. As part of that role we note and acknowledge the important role that fellow Queenslander Kerrie Keepa has played influencing the State Government to include people impacted by suicide in designing training for staff in emergency wards following the death of her son. This participation is essential to change attitudes and improve responsiveness to people who are contemplating suicide.

Conclusion

Support for people affected by suicide must be seen as an important and unique stream within the broader mental health services system. The needs of people impacted by suicide and attitudes to suicide overlap with those in the mental health system but are not the same.

Easier and more timely access to services, compassionate human centred, patient directed care within health services, and assertive follow up are crucial to saving lives. Provision for the inclusion of people with lived experience of suicide, who have received appropriate training and provided scaffolding of support in their peer roles, in all aspects of care is essential.

With increased support of people with lived experience of suicide, through organisations like Roses in the Ocean, we believe that Australia can save lives and reduce the impact of suicide across the nation. We must commit to building the capacity of our communities to identify people at risk, respond confidently and appropriately to suicide and support each other. People with a lived experience of suicide are well placed to be the drivers of this change and ongoing education within their community. We must ensure that initiatives within our communities are sustainable, relevant and accessible.

Furthermore, people with lived experience must be incorporated in all levels of system and service design as outlined in the Lived Experience Framework developed by the Australian National University for the Blackdog Institute (6). Their voices, experiences and expertise must be respected. Furthermore, their expertise must be utilised in non-clinical services that complement and reduce the demands on current medical models.

Roses in the Ocean thanks the Committee for this opportunity to provide an important perspective to addressing the national tragedy that suicide presents to our nation.

References