



Overview:

Caring Voices

Project



*Based on the stories
of Mental Health
Carers in Tasmania*

April 2015

For further information

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Mental Health Carers Tasmania thanks Tasmania Medicare Local for funding the Caring Voices Project and the following partner organisations for their involvement in the Caring Voices Project Reference Group:



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We would like to sincerely thank all the Mental Health Carers in Tasmania who took part in the Caring Voices Project in 2014-2015. We've heard your stories of love, hope, frustration and despair. Through the Caring Voices Project we will work together to make Tasmania a better place to be a Mental Health Carer.

Statistics are people with the tears washed off
Victor Sidel

Researched and written by
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Overview of the Caring Voices Project

Mental Health Carers have the right to be recognised, supported and respected in systems that work with them – not against them.

About our research methodology

The Caring Voices Project was established to gain further insight into the impact of key components of the caring role on the lives of Mental Health Carers in Tasmania. We invited Mental Health Carers to share their stories and experiences in relation to four key areas:

- The impact on Mental Health Carers of current government policies
- The needs of Mental Health Carers in relation to the transfer of care of their loved ones
- The impact of living arrangements for people with mental ill health on their Carers
- The impact of caring on the working lives of Mental Health Carers.

Our research involved 119 Mental Health Carers from across Tasmania. They spoke to us in person, via the telephone or in writing (including online questionnaires).

The Caring Voices Project resulted in the development of a series of position papers on the four key issues outlined above. We involved Mental Health Carers in both the development of our research tools and the position papers. **All the papers are available on the Mental Health Carers Tasmania website: www.mentalhealthcarerstas.org.au.**

Summary remarks

The Caring Voices Project provided a space for Mental Health Carers to share their stories about their experiences with caring for people with mental ill health. The stories were the result of both long histories of caring for someone with mental ill health, as well as more recent events. Some were positive and heart warming. Others were distressing and confronting. Some were long and complex. And often they were heart-breaking and very troubling. We thank all the Carers who had the courage to talk about their experiences and what were for many, very difficult circumstances.

Through the Caring Voices Project and the resulting position papers, we hope that readers will gain a deeper understanding of what it's like to be a Mental Health Carer. Of course, until we have lived the experiences it is never possible to know what it is truly like. However, it is possible for all of us to work together to create a more compassionate society. If we work on this we will contribute to embedding a culture of recognition, respect and support for Tasmania's Carers. A culture that needs to run through, not only our health system, but all of the systems that are implicated in the caring role, as well as the wider community.

One of the exciting things for us in undertaking this research is that we can use these findings to work for change. We believe that we can make Tasmania a great place to be a Mental Health Carer. There are numerous opportunities to do better. A commitment to Carer recognition, mental health reforms and the changing landscape of health services delivery, are among the opportunities we have to ensure that we raise the voices of Mental Health Carers to make the systems work better for them.

We look forward to seeing greater collaboration between systems, sectors, portfolios and services. It is not just for the health system to deal with mental ill health. This is an issue that requires a true commitment to working together. Health is determined by many factors – most of which lie outside of the health system and many of which are beyond the control of the individual. That’s why we look to governments for leadership on action on the social determinants of mental health – such as income, housing, transport, employment, access to health services and so forth.

Let’s take action

We conclude by summarising some of the actions that have arisen from our research. These are not all that is needed but they provide an opportunity to make a positive start:

Position Paper: Caring in a world of government policies

- ✓ We urge the Australian and Tasmanian Governments to provide adequate resources for the implementation of the Carer Recognition Act 2010 and the Tasmanian Carer Policy 2013, and to comprehensively evaluate the impact of the Carer Recognition Legislation/Policy on the lives of Carers (page 12).
- ✓ Further clarification, consultation and education is needed in relation to the issues of consent, confidentiality and Carer rights as they relate to the Mental Health Act 2013 and other relevant Carer recognition legislation/policies (page 15).
- ✓ Carers needs to be recognised in a broad spectrum of government policies - not just those related to Carer recognition or health - because caring implicates many government policies. It’s time to be serious about Carer recognition (page 20).
- ✓ As part of the Rethink Mental Health Project, policy developers should identify how to overcome barriers to accessing services for those with mental ill health and their Carers (page 28).

Position Paper: Navigating the road to treatment, support & recovery

- ✓ Mental Health Carers must be recognised, respected, involved and supported as part of the ‘care team’ for their loved ones (page 13).
- ✓ We urge those in charge of health service delivery to revisit the concept of case management. Mental Health Carers need access to long-term case managers that can work with people with mental ill health and their Carers on the journey to treatment, support and recovery (page 16).
- ✓ Support people with mental ill health and their Carers to ‘break the repetitive cycle’ by providing person-centred, long-term treatment plans and case management, and acting on the underlying causes of severe mental ill health. Perpetuating a system that continues to say that it is acceptable to repeatedly present to Tasmanian hospital emergency departments (often with the involvement of police) is not good for anyone (page 19).
- ✓ We urge the Tasmanian Government to explore opportunities to enhance cooperation between State and Territory health services in the interest of the health and safety of persons with mental ill health and their Carers (page 21).

Position Paper: *A place to call home*

- ✓ Adequate housing is a human right. As a community, we need to recognise the importance of a place to call home, particularly for good mental health. We must strive to ensure that all Tasmanians have access to adequate housing. We need to provide additional targeted support to people who are vulnerable, such as those living with mental ill health and their Carers. We must work together to solve this problem and we need committed leadership (page 9).
- ✓ Carer support needs better coordination and increased funding. Carers need more emotional (as well as financial and practical) support. Carers need to be recognised in their own right as well as for their role in caring for people with mental ill health (page 14).
- ✓ Collaborate - involving stakeholders from health, human services, police, education, economic development and the justice system - to explore better ways to prevent and respond to safety concerns and other complex problems associated with mental ill health (page 19).

Position Paper: *Caring – a job & a half*

- ✓ We need Carer-friendly workplaces that embed the principles of Tasmania’s Carer Policy 2013 and the Carers Recognition Act 2010 (page 15).
- ✓ Improving the employment prospects of both people with mental ill health and their Carers requires urgent attention (page 15).
- ✓ Stamp out stigma associated with mental ill health and caring for people with mental ill health (page 23).

Limitations of our research

While the Caring Voices Project may be limited by its sample size we also note that our sample was much larger than numerous studies reported in the literature. Our experiences in collecting data for the Project illustrated that sharing one’s experiences of caring for a person with mental ill health can be a highly emotive (and at times, painful) experience and we are grateful to the Carers who were able to participate in this process. We have sought to add strength to our Carer stories by triangulating some of our data and quoting relevant literature on research undertaken elsewhere. However it should be noted, that the primary purpose of this research was to simply publish what Mental Health Carers told us. There was no randomisation involved in the selection of our sample and there is likely to be some self-selection bias. Not all Carers involved in our research chose to answer all questions. Sample sizes are noted as ‘n’. The resourcing available to undertake the Caring Voices Project was significantly limited given the complexity of the issues surrounding the care of people with mental ill health.

Acknowledgements

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