

Submission by Sarah Sutton

We need to not just acknowledge the traditional custodians of the land on which we live and work and pay our respects to their elders past, present and emerging. We also need to show our respect by listening to and working with ATSI Australians to close the many gaps they face in mental health.

As consumers and carers, and particularly for people within marginalised groups, such as those with disabilities, those in prison, institutionalised, homeless, those from CALD or ATSI backgrounds, some of our experiences have been so horrible and traumatic. This is what keeps me motivated to continue advocacy.

It has been 25 years since Australia's first national mental health strategy. Around that time, one of my brothers became unwell. In 1991, my oldest brother was king hit at a party at the age of 21. He sustained an acquired brain injury and over time he withdrew from his friends, his family, his life. He wouldn't go to medical appointments, he stopped eating, he became distrustful of others. As he became more vulnerable he was taken advantage of by others including his friends.

My other brother, aged 17 at the time, perhaps from the trauma of witnessing all of this, quite suddenly also became unwell. He was seen at school engaging in risky behaviours and it was thought he was attempting to take his life. He went from a "straight a" student to a young man who wouldn't get out of bed to go to school and one day my parents found him hiding in a cupboard, extremely afraid.

Because of a lack of support by the mental health system, my brothers have difficulty getting motivated, organising themselves, learning new things, putting together ingredients to make a meal, communicating their needs, concentrating on complex tasks, and looking after their own health and well-being. People don't visit my brothers, they have no friends to ask them how they are, they don't get invited to parties, they don't work, they experience severe symptoms of mental illness and extreme side effects of medications such as diabetes, and the community discriminates against them.

One of my brothers does not talk as he was assaulted by police a number of years ago - for simply running away as he did not want to be detained involuntarily. He hadn't done anything wrong. Over the years he has been secluded and mechanically and chemically restrained against his will. His basic rights of communication and freedom of movement have been taken away.

As a sibling carer I have a fairly unique and very important but often undervalued perspective. Carers are often told not to speak on behalf of consumers. Our family has also been told on more than one occasion by service providers to "back away" and have a break. I can't tell you how much we would all LOVE a break. I cannot understand what it is like to have a diagnosis of schizophrenia, however I don't believe that I can NOT advocate for individuals who have diagnoses of severe and persistent mental illness, and in fact I ONLY participate in advocacy for them as no one else seems to want to do it for them or empower them to do it themselves. I am always torn as I want to honour my brothers' privacy but they are so disempowered by society and the stigma that surrounds mental illness that they have no voice and - no one asks them what they want. They have

no power and they are not given adequate support nor advocacy to make decisions for themselves. It is also really important to hear the voices of carers to gain additional information about a person, particularly if they are acutely unwell. When consumers are doing well, they are often not supported to develop advanced care plans for future situations when they may become unwell. In addition, consumers often cannot speak out due to fear of discrimination and mistreatment. A consumer can also be very scared of disclosing information about their experiences because of unjustified shame or for fear of being hospitalised and they will only talk about how this is impacting on their lives with people they trust – their carers.

These experiences leave me feeling so sad and upset and it is so difficult and almost impossible for me to stand by and watch the atrocities that are committed against my brothers by the ‘alleged’ mental health system, and the resulting consequences that they have on them and their lives. My brothers aren't seen as human beings, they are seen as burdens. They are NOT. They are kind, strong, patient, resilient, brave and gentle souls. That is why I speak up.

I worry too about those individuals out there that are in similar circumstances, but have no family or friends advocating for their rights. We especially have an obligation to those with a mental illness who do NOT have family members that love and support them, and do NOT have someone to advocate for them.

As such, I have invested significant time and effort participating in a variety of advocacy activities in the mental health sector, including involvement as a carer representative on expert advisory committees, mental health forums, and online forums in order to gain a greater awareness of the variety of carer needs. I am a SANE Australia Peer Ambassador. My family were featured in the first National Report Card by the National Mental Health Commission. I have large networks of carers at local, state and national level, and I am often called upon by carers to assist them in their caring and advocacy roles, including how to deal with feelings of isolation, grief and loss.

Common issues for carers include a lack of education about mental illness and the mental health “system” and how to navigate this, a lack of understanding about their legal rights and responsibilities, such as the Carers Recognition Act. People have a right to ask any service provider questions and know about the benefits and side effects of medications and treatments, adverse consequences, whether there are alternatives to what is being offered. Carers also experience a lack of inclusion in management plans even when a consumer consents to this occurring, often because service providers lack understanding about applying confidentiality rules. Carers also need support in learning how to balance family, work and caring responsibilities, including knowing how and when to prioritise these.

Carers desperately need more information and support – they are so busy in their caring role that they do not have time to attend information sessions and consultations – carers want to know about services and new schemes such as the NDIS, but they are confused and exhausted by this new scheme that is finally a light at the end of the tunnel for their family members, and they are often put off by media reports about the failings of the system.

People are not ill in isolation, particularly people with severe mental illnesses and carers in this situation often play a significant role in the support of their loved ones. Carers are the ones that continue to provide ongoing and daily support for those with complex mental illness diagnoses, even into old age. Our family are the ones that have written my brothers' NDIS applications, we are the ones that attend meetings for them and make complaints about their inadequate care – as my brothers cannot themselves complete these tasks and are not provided support nor assistance to engage in these processes. My family have spent the last 18 months attending Civil Administration Tribunal hearings in SA and a few months ago the matter was finalised, with our family successfully regaining control of my brother's money from the Public Trustee, who had earlier this year closed his bank account with no notice, and left him to flounder with no money for 6 weeks. Not 6 hours, not 6 days but 6 weeks! In SA, similar to other states and territories, there is no adequately supported accommodation available for people who struggle to live independently. My parents have bought my brothers a house to live in rent free for the rest of their lives and yet even this was questioned by the Tribunal.

The physical and mental toll that advocacy has had on our family is immense. We live in constant fear every day that something terrible might happen to my brothers, we have experienced many services drop out because my brothers are deemed 'too hard'. As a result of always being in fight flight mode, every member of my family has developed autoimmune conditions.

Of course, we will continue to provide assistance as a family, but my brothers actually don't want that kind of help from their family. Sometimes my oldest brother and I aren't quite on the same page. I'm his younger sister AND a psychologist, what would I know? Most often, my brothers and I just want to be siblings.

My career as a Psychologist for the past 18 years has also provided me with significant knowledge about the mental health system. I currently work as a Clinical Psychologist working in private practice in primary mental health care, a Forensic Psychologist working in the SA public service - but deliberately not working within mental health services.

There are great differences in power that I hold when I am wearing my different hats. If I am on a committee and I am introduced as a Psychologist with 18 years' experience in this role I hold substantially more power and credibility than if I am introduced as an individual who has two family members with schizophrenia diagnoses. This is despite the fact that I have ten years more experience in my caring role and I believe it provides me with a much better understanding of the effect mental illness can have on people's lives! I have experienced many situations where people cannot understand that my professional and lived experiences together provide a wealth of information and knowledge.

Consumers tell me often in my professional role or in my advocacy roles that they want treatment and support beyond the dominant medical model. The UN report on the rights of those with disabilities stated that the medical model of care is preventing good services. Psychosocial interventions, not medication, should be the first line treatment of mental illnesses. Human rights and social justice also need to be the core business of mental health services. The traditional focus on medical treatment and diagnoses and

labels are also NOT preventing people from taking their own lives and people are also continuing to become acutely unwell as they cannot access useful services, and people with a mental illness diagnosis have much shorter life expectancies than those without diagnoses. There are very few alternatives to acute care and the medical model, such that when a person is feeling distressed, suicidal and at risk of harm from others and is unsafe, they have NO ONE to talk to and work through this.

These are my ideas on how the mental health system should look.

First of all, 13% should be spent on mental health services – most countries only spend 2%, including Australia.

I believe that early intervention and holistic, peer and carer led supports are the way forward at all levels of need. All Australians need access to a choice of regular psychological, psychosocial and consumer and carer peer supports.

The National Standards for Mental Health were first formed in 1996 and are meant to be adhered to by all Mental Health Services across Australia. The standards state specifically that consumers and carers have the right to independently determine who will represent their views to mental health services”. This is NOT occurring. The standards also stipulate that consumers and carers need to be involved in all aspects of service design, planning and provision, but this is NOT occurring. Paid consumer and carer positions need to be created at ALL levels – on advisory boards, commissions, MBS reviews, within research projects, and they need to be remunerated fairly for their expertise.

Consumers need much more access to supported decision making, self advocacy and funded systemic advocacy. Each jurisdiction needs funded independent mental health advocacy services.

Paid peer workers and carer consultants are very well placed to undertake advocacy work in addition to providing support for consumers and carers. Service providers need to realise that experts are those with lived experience. If we wanted to know how to play the piano then we would ask an expert pianist. Why don't we ask those who have recovered from being unwell about how to do things better?

A Cochrane review found that peer workers are no better or worse than professionals, and other research demonstrates that peer workers can reduce hospital re-admission rates. All voices involved in a problem need to be heard. All perspectives need to be treated as valid.

When a project is consumer or carer led it looks different and BETTER. There are many peer led services which are effective, but are not readily available. These include alternatives to suicide, intentional peer support and survivor led crisis services.

The Power Threat Meaning Framework is another evidence-based model that is rarely utilised. The development of the Framework was funded as a project by the British Psychological Society's Division of Clinical Psychology. It was developed by practitioners and those with lived experience. The Framework uses mainly psychological and sociological knowledge along with recent biological research to outline a conceptual

alternative to traditional models of mental health and distress based on psychiatric diagnosis. The Framework summarises and integrates a great deal of evidence about the role of various kinds of power in people's lives, that misuse of power leads to people feeling threatened and that people have learnt to respond to those threats. In traditional mental health practice, threat responses are sometimes called 'symptoms'. The Framework looks instead at how we make sense of these difficult experiences and how messages from wider society can increase our feelings of shame, self-blame, isolation, fear and guilt. It is a trauma informed approach that asks what has happened to a person, how it has affected them, what sense they make of it, and what they have done to survive in those circumstances. The Power Threat Meaning Framework can be used as a way of helping people to create more hopeful narratives or stories about their lives and the difficulties they have faced or are still facing, instead of seeing themselves as blameworthy, weak, deficient or 'mentally ill'. It highlights and clarifies the links between wider social factors such as poverty, discrimination and inequality, along with traumas such as abuse and violence, and the resulting emotional distress or troubled behaviour, whether it is confusion, fear, despair or troubled or troubling behaviour.

Lived experience involvement needs to be included within services as KPIs and providing financial incentives for service providers to engage with those with lived experience would be welcome. We need to embed human rights into KPIs rather than "risk".

Peer workers and carer consultants need adequate support and supervision so they are not set up to fail or burnout in their roles. This requirement under the standards is NOT occurring. The Mental Health Standards also stipulate that the mental health services provide ongoing training and support for consumers and carers and staff which maximise consumer and carer(s) representation and participation in the services. This is NOT occurring. Additional activities are also required to develop the peer and carer workforce, so that more and more people with lived experience gain the relevant skills and training to undertake the work well. Paid consumers and carers also need to have clear processes for making complaints, without fear of retribution or punishments. Paid consumer and carer roles have decreased over the years in SA and other jurisdictions.

Each state and territory also need an independent, statutory body that covers promotion and early intervention, but also creates plans to support those that need it most. Ideally, a complaints commission that anyone using services, including peer workers and carer consultants, can utilise to create change and resolution of issues.

Overall, we need long-term health system reform, perhaps a permanent Australian Mental Health Reform Commission. An independent, legislated body – comparable to the Productivity Commission – charged with developing and overseeing a long-term health reform agenda that transcends our election cycles. Whilst the Productivity Commission has an economic and financial focus, the Australian Health Reform Commission would focus on finding ways to improve our health care system and health outcomes for all Australians. It will be a body explicitly charged with reducing health inequality and improving the universality of our health system. It will need to report not just to the Federal Health Minister but to all Governments through COAG – meaning a federal government will not be able to simply conceal or ignore inconvenient recommendations.

I would like to see a fully stepped care model established in each state and territory. It would be useful to compare the cost of hospital bed stays with the cost of increased funding to community mental health services, and observing the discrepancy in the costs that could be made from making community care the priority, with people discharged from hospital receiving increased support and services in the community and thus being less likely in the future to be re-admitted to costly acute/hospital services.

This is somewhat similar to the National Mental Health Service Planning Framework. Overall a focus on community care would result in significant cost savings for people with both moderate and severe levels of mental illness - whatever 'mental illness' means, I prefer to focus on people and symptoms and past trauma rather than diagnoses.

The stepped model of care requires thorough, evidence-based assessment of needs, such as mental health (levels of distress and symptoms) and psychosocial and environmental factors (family support, finances, lack of power). The level of need then determines the intensity and type of treatment or support needed. This individualised funding based on needs would be similar to the funding model utilised in the NDIS.

I have been lucky enough to be involved in a national expert advisory group for the past year or so where we have created a guideline for Primary Health Networks that assist in assigning a person to a level of care - as there is much talk about stepped care, but there has not been much achieved in Australia to determine a person's level of care that is required.

For those with that are deemed at a low level of need, they can be managed well by their GP, programs such as New Access, digital mental health services and peer workforce services, such as in South Australia the Lived Experience Telephone Support Service. The public need to have access to lists of bulk billing specialists and there need to be new Medicare items created for peer workers and carer consultants.

For those with moderate levels of need, they can be managed by the above strategies but also through 10 Psychologist sessions in the community through Better Access, programs through the PHN, psychosocial support and telehealth if required.

There is a huge gap in this country between the GP and ED. This is the missing middle. ALL people with mental health issues need easy access to the right support at the right level, at the right time, first time and every time.

For those with severe levels of need, they require intensive support and psychosocial rehabilitation through programs such as Partners in Recovery or the new Psychosocial Support Measure through the PHNs, state and territory mental health services or private care providers, in addition to specialist intervention. They need to have access to as many psychology and psychiatry Medicare sessions as they require, definitely above 10 per calendar year. Under the current system, you can see a Psychologist ten times a year, but you can see a Psychiatrist 50 times a year. People may also need assistance in making applications to the NDIS. Individualised funding packages with choice and control are a great idea, but people are confused about the NDIS and are not receiving the education nor assistance to make successful applications.

We need to focus on assisting those who have it hardest to access gap free holistic services, receive quality services and supports that focus on their whole of life needs, their functioning and services which have a biopsychosocial focus, not just a medical one.

One of my brothers saw a Psychologist a few times in the community and was never followed up, and my other brother has never been offered psychotherapy in the community to deal with the initial trauma which triggered his mental illness, nor to deal with the ongoing trauma that he has experienced over the years including the ongoing grief he experiences due to lost opportunities in his life.

We need integrated teams of professionals (Psychologists, Social Workers, Nurses, Occupational Therapists, Speech Pathologists, Psychiatrists, Exercise Physiologists, Dieticians, Physiotherapists, Podiatrists, Dentists, GPs, Aboriginal Health Workers, Support Coordinators and paid consumer and carer peer workers) to work together to give people the chance of a contributing life. Australians need help with mental health, dental health and physical and spiritual health – they need a one stop primary health care shop for all of these things where other factors like employment, housing, education, support and income are all taken into account. They then need quick and easy no-gap access to specialist services if required. It could also include access to specialists through public hospital outpatient clinics, similar to the specialist care that people in the community with cancer and other conditions receive.

There also aren't enough service providers that are caring, flexible, empathic, non-judgmental, compassionate and willing and able to spend time with consumers, sit with them, get to know them, and help him find hope and meaning in life. Some service providers have risked my brother's life and safety in the past as they would not change their services to meet his specific needs. Empathy and compassion is even more important in a worker than qualifications, and if the worker themselves also has lived experience of mental illness – well that is a super worker right there!

We also need much better evaluation of all services including the use of paid consumer and carer researchers - activity-based funding that rewards efficiency. Local, real-time feedback on consumer and carer mental health outcomes, to better reflect individual needs.

We need to make changes for ALL people with mental health needs, including those that have not yet recovered and are vulnerable and cannot speak for themselves. However, those who are vulnerable and in the minority need to be given power and support and not be expected to hold all the responsibility. This is what Janet Meagher spoke of in 2018 - the reluctance of the alienated.

Services have yet to learn how to properly overcome common barriers such as when a person is acutely unwell and distressed and does not necessarily easily accept the need for support. Recovery was introduced into mental health in order to ensure everyone was given the opportunity to live a better life, by providing an environment of hope around them. However, people are still falling through the gaps because they may be unable to articulate "goals and strategies to achieve those goals" in other words, they don't "fit" into the agencies' idea of what recovery means.

We need to share stories of hope and survival and demonstrate that things can improve with the right supports. I am given hope by consumer stories of braveness and resilience.

My brothers also inspire me daily, seeing them deal with the lack of support provided by the mental health system is very traumatic and the grief is immense, but it also demonstrates to me their great strength, resilience, persistence and patience.

Everyone deserves a contributing life, including safe and stable accommodation, good support and something meaningful to do with their time. We all need to work together better to pave a better future for others to live an enjoyable and meaningful life.