

## Carers

I am a mental health carer, having two brothers with Schizophrenia diagnoses.

I was disappointed with the Draft Report, as there was very little mention of carers. This is not surprising as there remains in Australia very little understanding and valuing of mental health carers.

For example, the Draft Report mentioned better training for peer workers but no mention of carer consultants to help families new to the MHS navigate services - this is essential!

As detailed in my previous submission (508) to the PC, it is so important for consumers and carers to be given information about mental health and the legal rights and responsibilities of and for consumers and carers, such as the Carers Recognition Act, and to be guided in how to navigate the mental health services. Carer Consultants often provide this very important role to both consumers and carers, particularly for those that are new to a service and are often experiencing overwhelming shock, grief, trauma and confusion.

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, even into old age. They are the ones that are writing NDIS applications for their loved ones, the ones that attend meetings for or with them, transport them to appointments, care for them in their own homes, make complaints about their inadequate care. The physical and mental toll that advocacy has on carers is immense, carers live in constant fear every day that something terrible might happen to their loved one, that services will drop out because their loved ones are deemed 'too hard' or too high risk. As a result of always being in fight flight mode, carers often develop physical and mental health conditions, including autoimmune conditions. In my family, there are numerous autoimmune conditions, including experienced by myself.

It is really important to hear the voices of carers to gain additional information about a person, particularly if they are acutely unwell. Sometimes consumers 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.

Carers, however, desperately need more information and support – they are so busy in their caring role and/or working that they do not have time to attend information sessions and consultations – carers want to know about 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 with complex mental health conditions and associated psychosocial disability and their carers also need much more education and support to apply for the NDIS. Consumers and carers are overwhelmed by the process, and they need support to navigate the NDIS process at the access, plan and implementation stages. The physical health care needs of people with psychosocial disability also need to be urgently addressed.

It is really important for consumers and carers within services to gain advice from those with lived experience and living experience, and to hear positive stories of hope from both peer workers and carer consultants. This is why it is so important to have Carer Consultants being employed in all services. There also needs to be much more information on involving carers, and including carer information and involvement as measures of success.

Many service providers also fail to understand the principles of confidentiality. "A Practical Guide for Working with Carers of People with a Mental Illness" was developed by a number of organisations and provides information to assist service providers support carers in their role as partners in recovery. For example, it explains that confidentiality is not breached when service providers seek or receive information from family members to assist with diagnoses or the development of care plans.

[https://www.mindaustralia.org.au/sites/default/files/publications/A\\_practical\\_guide\\_for\\_working\\_with\\_people\\_with\\_a\\_mental\\_illness.pdf](https://www.mindaustralia.org.au/sites/default/files/publications/A_practical_guide_for_working_with_people_with_a_mental_illness.pdf)

Family carers remain as isolated and marginalised as ever. Governments tend to ignore the experience and insights of people on the ground. Families remain invisible to governments, policy makers and services.

However, it was positive to note that the PC Draft Report recommended including carer consultations within the MBS. I fully support the recommendation that the Australian Government should amend the MBS so that psychologists and other allied health professionals are subsidised:

- to provide family and couple therapy, where one or more members of the family/couple is experiencing mental illness. These sessions should count towards session limits for psychological therapy;
- for consultations with carers and family members without the care recipient present. This would be consistent with existing items that are available to psychiatrists, there should be a limit of four subsidised consultations with carers and family members per 12 month period. This is a good start, however some carers and family members may need more than this, and to be effective, the number of sessions should be matched to clinical need.

In addition, to better meet the needs of carers whose care recipient has a mental illness, the recommendation that the Government should amend eligibility criteria for the Carer Payment and Carer Allowance to reflect that: the nature of care provided for someone with mental illness is not necessarily as 'constant' as that for a physical illness, can vary substantially from day to day, and is less likely to relate to the care recipient's 'bodily functions', is very positive. To provide more flexibility for the carer in undertaking their own economic and social activity, the restriction on hours that the carer can work or

volunteer should be evaluated over a month rather than each week, and the restriction on study should be removed. Although I am an unpaid carer, I fully support these recommendations.

### Complex mental health needs

There needs to be much more focus on lived experience workers – peer specialists AND carer consultants. The Draft Report stated that not all mental illness requires medical care, and that sometimes group therapy and peer work can have a positive impact on people living with mental health concerns. However, this would be useful for all levels of severity and is often much cheaper than health professionals – although the peer workforce should not be seen as a devalued approach. The peer workforce needs to build in capacity, which requires mandatory supervision, mentoring, professional development and the opportunity for career progression to leadership roles with increased experience.

The Draft Report also recommended that people with more severe forms of mental illness also require high intensity, often multi-disciplinary care, from specialist services delivered through MBS-rebated or government salaried psychiatrists and expanded community-based clinical services, with service continuity between primary care and acute/specialist care. How will this occur? The planned Adult Mental Health Care Centres in each State/Territory will go some way towards addressing this, however these centres will need to be expanded beyond the eight planned.

The Draft Report recommended that the number of publicly-supported places double to 20 for patients with complex conditions. However, number of sessions needs to be linked to clinical need. Some people require 10 sessions and some require 40 or 50 sessions per calendar year – if this need can be demonstrated, in addition to the demonstration of the effectiveness of interventions for a specific person – then a person should be able to access the number of sessions required to meet their specific needs.

### Cost

One of the biggest concerns for patients is around the cost of mental health support. What would be useful for consumers and carers is having access to a list of bulk-billing professionals, in addition to being able to access consumer and carer supports under Medicare.

### Independent lived experience peak bodies

When consulting with consumer and carer peak bodies this needs to include independent bodies led by lived experience, otherwise the peak bodies priority is serving non-government organisations. In reality, Australian non-government peaks do not represent consumers, they represent organisations that provide services to consumers. They don't permit consumers to speak for themselves. Of the independent peak bodies, most are consumers only which therefore does not often include those with complex needs who, through lack of support, have no voice. This includes my brothers who had a lack of formal

supports for almost 30 years. There are no independent carer bodies run by carers in SA, the state in which I live.

### Forensic

On justice-related issues, the Draft Report says the Australian Commission on Safety and Quality in Health Care should review the National Safety and Quality Health Service Standards to ensure that they apply to mental health service provision in correctional facilities. The Draft Report recommended that all people who are entering jail or other institutions be screened for mental health concerns, and given appropriate treatment if one is identified. I wonder how this will be addressed when the focus of jails, and thus the funding for state based correctional facilities, necessitates the focus to be on safety and security.

The Draft Report recommended that mental health professionals be embedded with police, to help de-escalate situations in which officers respond to people who might be experiencing a mental health episode. This used to occur much better in SA, with people with lived experience providing education and advice to first responders. The report did mention that exposing health students and practising health professionals to people with a mental illness (and their carers) outside a clinical environment to help break down negative perceptions can be useful. This is essential.

### Housing

There is a big link between untreated mental illness and homelessness, and the Draft Report states that governments should create more supported housing spots for people with complex or severe conditions. However, how will this occur? The NDIS provides a great opportunity for non-government organisations to build core and cluster type housing, but so far there has been very little uptake of such innovative models by NGOs that have proved effective in Nordic countries.

### Community Services

The Draft Report states that there is a need for much more community services including sub-acute. One of the centres that was planned for SA never opened and one closed in recent years. One now only offers step down and not step up. Figure 5 in the report shows that supported accommodation is MUCH cheaper than acute care. We also need non clinical alternatives to ED. Community services need to definitely be incentivised in a similar way to how acute care is currently funded.

### Cultural Changes required in Mental Health Care

People are not hard to reach but we need mobile assertive outreach teams to meet their needs and overcome common barriers to treatment.

We need ONLY empathic, flexible, genuine, caring people working in mental health which will necessitate better screening of the workforce. Therapeutic alliance is the BIGGEST predictor of effectiveness with any therapeutic intervention. However, services are still

provider-centric, impersonal and fragmented. Therapeutic alliance needs to be routinely measured and reported on for all services.

The Draft Report suggested that governments and specialist medical colleges should take further steps to reduce the negative perception of, and to promote, mental health as a career option. This is a strange recommendation. If someone has a negative view of mental health issues, then this is NOT the area for them to be working in.

We need to be much better at empowering consumers and their families and carers. Why ISN'T the first step in accessing mental health services asking the person what they are seeking and what they would like to gain from services? For example, assessment, connection, assistance with problem-solving, speaking to a peer worker, medication, a safe place. THIS needs to be the initial and ongoing driver of all services.

The physical environment of mental health services also needs improvement. Although not often designed for such, outdoor areas are commonly used for grieving and cultural rituals around death for Aboriginal and Torres Strait Islander populations. Outdoor spaces deserve as much design attention as the interiors. People with lived experience want comfortable, safe, accessible spaces. Aboriginal and Torres Strait Islander people also have an holistic concept of social and emotional wellbeing. Many features of ATSI health and wellbeing models - including physical design of services and also models of care - could be used effectively for all populations.

### Stigma

The Draft Report states that high levels of stigma remain for those with diagnoses such as Schizophrenia, in fact there has been an increase of perceptions of dangerousness in those with such a diagnosis. I agree with the Draft Report that stigma interventions need to assess behaviour change not just intentions, and recovery camps where service providers and consumers live together would be one useful way to achieve this. Another program which addresses stigma is the SANE Australia Peer Ambassador program, whereby consumer and carers provide education and input to a variety of audiences, including individuals who work in mental health but also non-mental health audiences. I myself am a SANE Australia Peer Ambassador. Stigma reduction and education programs need to be available in schools – a person with a lived experience of mental health issues delivering this education will enable simple explanations and provide a diversity of experiences and will encourage help-seeking behaviour from an early age.

**Sarah Sutton**

South Australia