



Carers ACT

What do ACT mental health carers need from mental
health clinicians?

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Introduction

One recurring issue in mental health carer advocacy has been that mental health carers feel confused, unsupported, overwhelmed and/or excluded by the very mental health system that treats the person they care for. Whilst this is particularly conspicuous in the inpatient unit setting, carers also report it as the reality across community mental health as well.

The ACT has been a progressive advocate for carer inclusion in mental health treatment and care and has many visionary documents that support the ideal of good carer engagement. This includes the ACT Mental Health Act 2015 (Mental Health Act, 2015), which became legislation in March 2016. The principles of the Act are clear, and carers are viewed as pivotal partners in care to be worked with respectfully and supported in their role. However, in practice, mental health carers in the ACT continue to report that they do not feel listened to or supported in their caring role by mental health services, and specifically by the clinicians involved in the care of their loved one.

On the 26th of June, 2017 a group of mental health carers from the Canberra region came together to deliberate on what they believe 'good mental health carer engagement' would look like. The aim of the session was to get a detailed description from mental health carers themselves of what they need from mental health clinicians and then to provide this feedback to mental health services to guide how they engage carers.

Methodology

Carers were provided with evidence from a range of sources (see appendices) advising on how they could be involved in mental health care. The carers engaged in a number of deliberative processes to discuss the recommendations of the evidence and to prioritise the issues to meet the needs of carers in the ACT.

The deliberative process was used as it concentrates consultation on the ideal and potential solutions to current negative experiences. It takes people outside of their own experiences and broadens the focus to all carers. It also is a very evaluative process whereby carers are in a thoughtful and reflective space where there is disagreement, negotiation and consensus for different ideas.

The first task was reading and evaluating comments that were distilled from recommendations in the literature. They were also able to add their own suggestion in for consideration. They then had deliberative one-on-one conversations with each other and compared statements on how important they were, how valuable they would be to carers and whether they believed it to be a responsibility of the mental health clinician(s). Carers scored the statements out of 7 for each conversation and had 5 conversations with other carers.

The statements and their scores were then written onto a white board and totalled. As a group, we were then able to go through and see that some statements were very similar and central themes arose. Some of the recommendations that carers had written themselves were able to encapsulate ideas better than the recommendations from the papers. The carers then selected the priority areas as a group, and worded them together. They arrived at four priority areas and then the final task of the day was to take one priority area per table and develop a basic program logic for how that could be implemented and/or achieved. In going into the program logic phase, we asked carers which clinicians had engaged with them well and what they did that was different. We asked carers to think about why that doesn't happen every time, what are the barriers for clinicians and what would help them overcome those barriers.

Results

The four priority areas identified by mental health carers were;

1. Carer Wellbeing and Coping
2. Information about diagnosis/symptoms and treatments
3. Safety and Legal
4. Inclusion: recognition of the carer's expertise and role

This article shall unpack these four priority areas based upon the comments carers made within the session and the supporting literature for positive carer engagement. This document aims to provide a platform for improving mental health carer engagement in Canberra.

Priority Area 1. Carer Wellbeing and Coping

Research continues to confirm that caring for someone with a mental illness can negatively impact health and wellbeing. Whilst undeniably carers report wanting to care for their family member or friend, many experience as a result increased distress, grief, loneliness, anger, shame, despair and worry (Reinares et al., 2006). Mental health carers are more likely than other carers to report higher rates of carer burden. In a study by Perlick et al., (2008) 93% of mental health carers reported at least moderate burden. Also, compared to the general population in Australia, carers of people with mental illness had more mental health symptoms or were more likely to have a mental health diagnosis (Pirkis et al., 2010).

In the deliberative discussions with mental health carers, carers found this to be an area of concern. One carer commented that they felt they had to walk a very narrow line and be very regulated in their emotions.

"It's really stressful, the person you care for is really unwell and you're worried and no one is telling you anything. But you know you can't show you're upset. Then they would think that

you're crazy or a troublemaker. But if you don't push then you don't get any answers. You have to push but you can't get upset."

Others expressed that they felt pressured in the discharge process, and that the focus was on needing to free up the beds, even when the carer didn't feel capable or confident in caring for the person again. Carers recommended that before staff are making decisions to discharge that they make warm referrals across to carer supports. It was stated that they already felt it was difficult to admit to needing help and that having the health service normalise that as part of discharge could help them to cope.

It was also recommended that in discharge planning discussions, carer wellbeing was prioritised. Carers did not feel they could say no to having the person they cared for discharged into their care, even if they felt they couldn't provide care, felt unsafe or felt financially vulnerable.

Many of the other priority areas overlap with this one, as they increase stress and decrease wellbeing for carers of people with mental illness. However, within this area it was clear that carers felt their rights and needs were considered as secondary to the person they cared for's, and to the needs of the mental health service. They felt that there was pressure from services to behave a certain way to have their voice heard. They also thought that the mental health services could be more proactive in getting carers to access supports for themselves.

One carer mentioned that getting supports for themselves was like putting on your oxygen mask before helping others in a flight safety demonstration. *"We all know we should do it, but you need someone to tell you, do it! It feels selfish, but it will help you to be able to care for them and you need permission almost."*

In the program logic that carers developed they started with aiming for the outcome:

The outcome we aim for is that carers have high wellbeing and they are coping well

To achieve this, they said that carers needed information about their caring role and about the person they cared for, confidence that their needs were important to decision making, permission to be human and to need help, but also acknowledgement that this doesn't mean they don't want to participate in discussions.

They said that carers need to be healthy, physically, emotionally and mentally to be able to cope with mental health caring and need to be actively encouraged to get help for themselves and thought the idea of a warm referral could improve the uptake of carer services.

Priority Area 2. Information about diagnosis/symptoms and treatments

When caring for someone with a mental illness, especially early in a carer's journey it can be very difficult to get accurate information. There is a great deal of information available on mental illness but knowing what to trust and whether it is relevant for the person the carer is caring for is difficult. Whilst resources such as information sheets, websites and online forums were useful for carers, many said that they wanted information that was more tailored, more specific information about the illness of the person they cared for, what symptoms they could expect and what treatments were recommended.

Carers believed strongly that this information was crucial to helping them in their caring role and that it made the situation seem more manageable. In situations where patients were not wanting details to be shared with their carer, carers said that they would still appreciate a conversation with the clinician regarding generalities of the diagnosis, ie. people with a diagnosis of schizophrenia often have symptoms of... recommended treatments usually include ... etc.

In other discussions, especially in the inpatient mental health services, carers have articulated an interest in receiving copies of recovery plans to help them to support the person they care for. This as a suggestion has always received mixed responses, with some saying that they recovery plan itself was not detailed enough to be helpful and did not meet the carers perception of the consumer's needs. Also, many felt there was more value in the conversation rather than the documentation. Others said they hadn't seen one, however if it included upcoming appointments or medications and doses then they could help remind the person they cared for about them, which would be '*better than nothing.*'

Information about diagnosis, symptoms and treatments were simply the first steps for carers and it was also mentioned during the workshop that skills training would also be helpful. Accidental counsellor training, ASSIST training, mental health first aid training were all mentioned in a program logic filled in at the workshop, unfortunately we did not have time to discuss these comments with the carers involved. However, the comments suggest they wanted information from staff about where they could get training and what training would be useful, ie. recommendations about good training programs available rather than the staff to provide carers with that training.

The program logic that carers developed for this priority area identified that the results of greater information to carers would be both increased positive clinical outcomes for consumers and improved carer-clinician relationship. In addition to that, from the above priority area, carer wellbeing would also possibly improve.

It was recommended that these could be measured by number of repeated admissions to the inpatient unit, and for those treated in the community context, it could be measured through attendance at appointments etc. It was also recommended that carers' experiences of service in mental health be regularly gathered.

Carers also want an opportunity to provide information about the how the person they care for has been at home as well. This shall be explored more in Priority Area 4.

Priority Area 3. Safety and Legal

A diagnosis of a mental illness comes attached with a history of stigma, discrimination and social prejudice. There has also been a history of seeing people with a mental illness as dangerous and unpredictable which continues to persist for many people today. To further complicate this mix, people with severe mental illness can experience impaired decision making capacity as a result of their illness, which can impact on their ability to seek treatment for themselves, but also to be held criminally responsible for the actions under criminal law.

As a result, in Australia and many parts of the world, legislation has progressed to provide protections for people with a mental illness and uphold their rights but also to provide for treating and detaining someone who does not want treatment when safety is a concern.

For people working in mental health, this is a normal and commonplace thing to see and experience. Terminology in the ACT includes many acronyms, common slang and terminology that is foreign information to many people entering the mental health system.

During the workshop with mental health carers it was clear that most had been quite unprepared for the legal aspects of being a mental health carer. They said it was like learning a new language, because;

“One person would call it a PTO, the next would call it being ‘under orders’ the next would say he ‘had treatment order in place’ then people were talking about going to ACAT or tribunal and I didn’t know if we needed a lawyer. It all happened so fast.”

Carers at the workshop reported needing more information at the beginning. That it needed to be explained slowly and patiently. Of the carers at the workshop many did not realise that the mental health legislation in the ACT had recently changed or how it had changed. Some carers had said that they had trusted the doctors that everything necessary was being done, and did not realise that they had other legal options that they could utilise. This included information about applying for guardianship orders or organising an external party to manage the consumer’s finances. One carer hadn’t had the full implications of Psychiatric Treatment Orders explained to her for her situation.

Whilst carers did not expect clinicians to quote pages of legislation, they wanted plain English explanations of what was happening that acknowledged that many people had little or no experience with the legal system. They also wanted to be informed of how the Mental Health Act 2015 upholds their needs as carers and therefore what they can expect of mental health services. They also wanted information on where to go for more information.

Also as part of this conversation, rights of carers came up as a topic and also carer safety. Carers articulated that in general they did not think that their safety was a concern that staff

actively assessed. This closely tied to carer wellbeing, but it was seen as more fundamental to the clinician's responsibility to ensure that the carer was going to be safe upon the consumer's discharge from an inpatient facility or, within the community setting, with changes to the consumer's treatment or with deterioration in their health. This is especially important for carers living with the people they care for but also for carers who live separately who have concern for other family members or themselves when they visit.

Carers wanted clinicians to understand that they often did not want to discuss the most difficult parts of caring, especially violence, with the person present.

Priority Area 4. Inclusion: recognition of the carer's expertise and role

Consistent with feedback received from carers in many different mediums, the carers within our workshop reported that greater inclusion and recognition of them in their caring role would be fundamental. Carers know the person they care for very well, they know how they are when they are well and what they are like when they are unwell. They will often know their treatment history in detail and be able to facilitate implementing treatment plans or recovery plans between visits to the treating team. For carers, not being included in decision making around treatment options is insulting and devaluing.

In research commissioned by Mind Australia, it was estimated (quite conservatively) that mental health carers save the Australian Government \$13.2 billion every year with the care and support they provide (Diminic et al., 2016). This does not include the figures on young carers who are under 15 years of age caring for a parent with a mental illness. Maybery et al. (cited in Diminic et al., 2016) estimated that between 14.4 and 23.3% or approximately 1 in 5 children live with at least one parent with a mental illness. This does not mean they are the primary carers however, it is important to acknowledge that carers come in many shapes and sizes and should be included to the extent that is appropriate and respectful of their role.

As part of including carers as 'partners in care' it is important to ensure that it is meaningful and that clinicians are open to changing or adapting plans. Carer inclusion should not be undertaken to develop 'carer buy-in' to a treatment but rather as a discussion, as gathering as much evidence and discussing what solutions might exist as a team. The dynamic should be of one of equals discussing the best possible steps forward.

If consumers do not wish the carer to be included in the treatment discussion, it was raised by a carer that it would be beneficial if a discussion could be undertaken between the consumer and clinician about finding out why and explaining why it was important, what would be discussed, and that certain details could be kept confidential etc. to unpack their decision and ensure that it was fully informed.

In the discussion, many carers raised that the principles of the ACT Mental Health Act 2015 were very positive for them and if they could be realised in a practical sense – their caring role would be far smoother and less stressful.

Paraphrased below as;

6. Principles applying to Act

*In exercising a function under this Act, the following principles must be taken into account:
(...)*

(j) services provided to a person with a mental disorder or mental illness should—

(ix) facilitate appropriate involvement of close relatives, close friends and carers in treatment, care or support decisions in partnership with medical professionals; and

*(x) acknowledge the impact of mental disorder and mental illness on the close relatives, close friends and carers of people with a mental disorder or mental illness;
and*

(xi) recognise the experience and knowledge of close relatives, close friends and carers about a person's mental disorder or mental illness; and

(xii) promote inclusive practices in treatment, care or support to engage families and carers in responding to a person's mental disorder or mental illness

Conclusion

It was clear from undertaking this workshop that carers were experiencing similar experiences and were consistent with many other mental health carers in their experiences across Australia. It was also beneficial to identify these priorities for the ACT region specifically. In developing the 'how?' for achieving these changes, it was identified that much of the work has already been done, with the Mental Health Act echoing the same sentiments and many of the services already existing in the ACT.

In response to this feedback from carers, the Mental Health Carers Voice suggests that carer specific training is rolled out across the ACT mental health services to develop these into practical skills for all staff and utilise the work that is being undertaken with the evaluation of the Mental Health Act implementation to measure outcomes of the sessions.

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Appendices

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