



Carers ACT

Findings Paper from 2018 Priorities Survey

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February 2019

Carers ACT acknowledges that modern day Canberra has been built on the traditional lands of the Ngunnawal people. We offer our respects to their Elders past and present, and celebrate the Ngunnawal people's living culture and valuable contribution to the ACT community.

Who is Carers ACT?

Carers ACT is a non-profit, community-based, incorporated association and registered charity dedicated to improving the lives of the estimated 48,850 carers living in the Australian Capital Territory.

These carers provide ongoing unpaid care for people with disabilities, mental illness, chronic conditions, who have palliative care needs, or who are aged and frail. Carers ACT currently provides direct support to around 8000 families through our counselling, information, respite support, education, social support and case coordination services. We continue to meet national accreditation standards for delivery of our services to carers at a high level.

Carers ACT has a constitutional mandate to represent the voices of mental health carers to government and the wider community. We actively consult with a wide diversity of caring families on an ongoing basis to enable improved understanding of their needs, and enable better inclusion for them and the people they care for. Policy work in consultation, research and representation is kept separate from service delivery to ensure that the privacy of individual service recipients is respected. All carer participation in policy work is voluntary.

Executive summary

In 2018 the Mental Health Carers Voice program undertook a large-scale survey on mental health carers and their recent experiences engaging with mental health services and carer supports. The survey was distributed to our membership and through our partner organisations to distribute to theirs. The broad distribution of the survey was specifically undertaken to seek input from those who had not previously identified as a carer or had not had the need to engage with our program previously.

The survey had a mixture of multiple choice and short response questions and was designed to take approximately 30 minutes to complete. The survey captured valuable insight into both positive and negative experiences of many mental health carers and will guide the policy and advocacy work that the Mental Health Carers Voice program undertake going forward.

Those surveyed identified their recommendations for improving the experience of being a mental health carer. These responses were many and varied but consistent themes emerged, and responses were grouped under the following areas for focus.

1. Increased quantity and quality of Mental Health Services
2. Improved awareness in non-mental health services about mental health and caring
3. Carers need to be included, respected and supported in their role
4. Prioritising wellbeing through early intervention and care coordination to create mentally healthy communities

The results of the survey have demonstrated that there is inconsistency between the perception of the mental health system and the individual carer experiences. It has also highlighted the ongoing issues regarding carer inclusion and carer wellbeing.

This survey specifically targeted carers with recent experiences of interacting with mental health services and it would be recommended that this survey be repeated approximately every 2 years to determine whether the experience is improving.

Methodology

The survey was a descriptive design utilising predominately quantitative research questions with a mixture of open-ended and close-ended questions. Participants were recruited through an advertisement that went to the Carers ACT mailing list of mental health carers and was also distributed to other partner organisations including other health peak bodies and mental health service providers. The sampling was then voluntary and targeted at current mental health carers, although others could participate, including consumers, consumer/carers and organisations that worked closely with mental health carers. The survey was completed online using SurveyMonkey.

Due to the descriptive design and number of respondents, inferential statistical analysis was not appropriate, and the data analysis has focused on quantitative statistics for close-ended questions and thematic analysis for open-ended questions.

Results

46 people participated in the survey, of those 78.36% identified as a current mental health carer, 10.87% as a mental health consumer and carer and 4.35% as having previously been a mental health carer. 3 participants responded as other and clarified in their descriptions that the person they cared for also had other disabilities in addition to mental illness/mental health disorders.

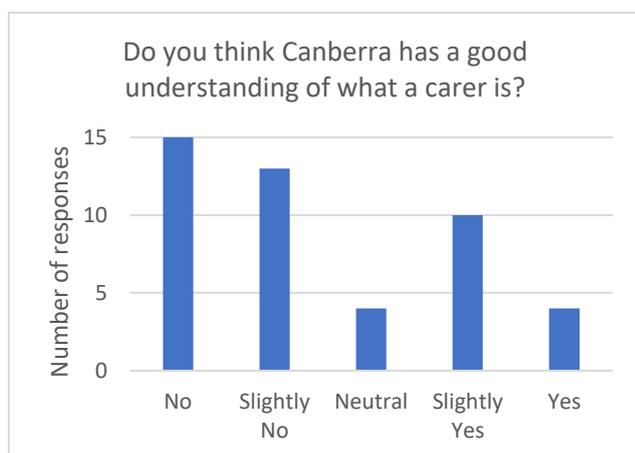
The first three questions participants were asked to respond with No, Slightly No, Neutral, Slightly Yes and Yes. These responses were then converted to scores out of 5. With scores closer to 1 indicating more responses negatively and scores closer to 5 as more affirmative.

	Question	Weighted Average
Question 2	Do you think Canberra has a good understanding of what a carer is?	2.46*
Question 3	Do you think there is stigma about being a mental health carer?	3.78
Question 4	From your experience, do you think mental health professionals understand who carers are?	2.76*

Figure 1: Table demonstrating questions and weighted average of responses to questions 2, 3 and 4.

*The neutrality of these responses was more indicative of answers at either ends of the spectrum demonstrating lack of consistency of experience more than neutral experiences.

Figure 2 and 3: Graphs demonstrating spread of responses to questions 2 and 4.



Of the 46 respondents in question 5, 80.43% had sought carer supports and 19.57% had not. Reasons that carers provided for not seeking support for themselves included lack of time, feeling like they were coping well and that other people may need it more and feeling that the services were unable to help them and/or having had previous negative experiences.

Of those who reported having used supports two consistent themes emerged. Firstly that they had needed to be pushed to get help for themselves and/or it had taken them a while to accept help and also that they wanted to know how to better support the person they cared for. Respite, counselling, advocacy and education all came through as valuable.

Questions following these were asking for carers to review their recent experiences interacting with mental health services. 80.43% of respondents reported to having interacted with the mental health services in the ACT as a carer in the last 18 months.

Question 7 asked respondents to identify the services they have been involved with. One carer stated they were interacting with mental health services between 2012-2014. A majority indicated accessing multiple services over the last 18 months.

Table: Services Carers had inter

Service	Number	Break down
Hospitals	11	Canberra Hospital 4 Calvary Hospital 6 (including 2N) Other 2- St Vincent's Hospital Hyson Green
Community Mental Health	13	Phillip Mental Health 4 Belconnen Mental Health 4 City Mental Health 2 Gungahlin Mental Health 2 Adult Mental Health Treatment Teams
Psychological Services	8	Includes 2 private psychologists
GP	5	
Adult Mental Health Unit	7	
CATT	5	
Older Persons Mental Health	1	
CAHMS	4	
Specialist Youth Mental Health Services	2	

Figure 4: Breakdown of most frequently mentioned services that carers had engaged with and how many carers mentioned them.

Other services/ programs	
<ul style="list-style-type: none"> • Ambulance • Headspace • Help lines • NDIS • STEPS • MHCN 	<ul style="list-style-type: none"> • Public Trustee/Public Advocate • Dementia ACT • Carers ACT • School counsellor • Rape crisis • Support group in Griffith

Figure 5: Other services and programs that carers mentioned specifically.

Question 8 asked respondents to describe which was the best service for them as a carer, and why, prompted a variety of responses. Six carers stated they found psychologists supportive. Comments included *'they took the time out to listen to me also'*. Another stated the *'School Psychologist was very helpful and freely gave of her time'*

One carer stated they found the ambulance officer to be most supportive *'I felt supported. The ambulance officer said he wouldn't abandon me until we got the help we needed for our daughter'*. For two respondents GP's were their best support

Another carers stated *'Headspace has been wonderful and supportive. They take the time to explain to carers what's happening and, although the counselling is confidential, they let you know when they're worried about the safety of the consumer.'*

Comments in relation to why a respondent thought a service was best included:

- *'Community Team - staff spending time to talk and able to call and speak to same person'*
- *'As always it is the person or persons that you get. Currently we have the best clinical manager we have ever had. In our 12 years of being in mental health system we have only had 2 good case managers. Having a good case manager makes a vast difference and we would love to clone our current one as she is gold'*
- *'although not accessed in recent times PHAMS was by far the best both for myself and my partner as it was non-stigmatising and based on real experience. My partner is sadly "too well" to access this anymore which is a great disappointment'*
- *'being kept informed of the progress when medication was reviewed'*
- *'well trained staff'*
- *'Ward 2N-The treating psychiatrist made an effort to include me in some parts of the decision making relating to treatment during the hospital stay for acute care'*
- *'Mental health foundation or step up step down program because it provides a break for myself whilst my mum is in care and suicidal'*

Three respondents highlighted the benefits of carer services:

- *'ACT Carers as from my experience they appear to understand the well-being of the Carer's situation. I have benefited from several workshops they have run, counselling and a break from the daily grind. As a carer you have to be available 24/7 which is exhausting both physically and mentally'*
- *'Carers support Services. Because it gives me a chance to be with likeminded fellows and be inclusive.'*
- *'Carers ACT because my interactions with them have been about me whereas the Rape Crisis Centre has been for my daughter who I am the carer of.'*

Six carers stated in this section that they couldn't think of a good service experience and they had had purely negative experiences in their interactions, *'it was a bad experience'* and *'it hasn't personally helped me'*.

Five participants chose not to answer this question.

In the next question, participants were asked about their worst experiences, specifically for them as a carer. Of the 41 people who responded, 11 responded that they did not have a worst experience,

comments included *“No real issues”, “Both excellent” and “Neither are bad services - both have been wonderful in the support they have provided when required”*. These respondents had utilised services through Carers ACT, Canberra Rape Crisis Centre, Calvary Older Persons Health Service, The Adult Mental Health Unit and a Community Mental Health Treatment Team (unspecified). Northside Psychology and GPs were also mentioned positively.

CAMHS was mentioned as being the worst for four respondents (which was every respondent who had interacted with the service), CAT Team was mentioned by three (of five) respondents;

- *‘They are not proactive enough in a crisis and keep closing the books on my daughter despite her long-term illness. They keep putting her care back onto the family when they know we need support eg daily, in-home administration of her medication and monitoring’*
- *‘CAMHS was ridiculous!! Long waiting times for appointments. They say things like “make sure you lock up all sharp objects and poisons, monitor your child in the bath/shower and go through their room to remove any dangerous items” and then go on to say “you’ll have to wait 2 months for an appointment”, no offer of supports in the meantime. The first GP we went to following my daughter’s suicide attempt last year listened to my daughter’s problems, didn’t offer any advice to me or my daughter on how to care for her mental illness and then patted her on the shoulder and said “you’ll be right” and led us to the door. My daughter had just relived all of that trauma by telling her story. I then went GP shopping to find someone who actually knew about mental health. My psychologist suggested a few GPs who were really good with mental health issues (most weren’t accepting new patients). We now have a really good GP who initiated a mental health plan for my daughter.’*
- *‘HORRIBLE service. They did not have a clue. All they were interested in was ticking boxes to keep themselves covered. Very judgemental organisation and actually made things worse for my child and therefore me and my family’.*
- *‘CAMHS - despite self-harm and suicidal ideation, gender dysphoria and disruption to normal activities my child was not deemed to have severe needs’*

Tuggeranong Mental Health and Woden Mental health were mentioned each once. The hospitals, both Calvary and Canberra Hospital were mentioned multiple time, in particular comments about difficulties in the Emergency Departments,

- *“Emergency Department at Calvary. The mental health nurse conducting triage was very dismissive of concerns expressed by both myself and the care recipient and was pressuring the psychiatric registrar to send us home, during a very dangerous period.”*
- *“CAT team and Canberra hospital not much help and don't understand what carers go through when the person they care for is in crisis”*

Approximately 10 responses referenced that being a mental health carer accessing services generally and the wider community was a highly negative experience. Comments included;

- *“having no one and feeling isolated because of stigma still out there in society”*
- *“All of the public services combined. There are significantly harmful cultural issues that need addressing. Stigma, us vs them attitudes, paternalism, disrespect, to name a few.”*
- *“Psychologist - excluded from care plan”*
- *“Mental Health medically send to take my son off medication for outbursts of violence when we took him off this he was beating into everyone including himself causing major crisis”*
- *“Over the years we as carers and our loved one have been further traumatised by services that were meant to support us the worst being: city mental health, Belconnen mh and adult*

mental health unit. We as carers will do everything we can not to have to deal with these services again.”

- *“I was treated as if I shouldn't be there and that I knew the 'rules'.”*

One comment was centred around the carers experience of the Adult Mental Health Unit, however commented on a wider concern regarding the implementation of the Mental Health Act 2015 in the ACT generally.

“AHMU as if your loved one is admitted they have been very unwell and things are at their toughest. Then they dont care about you and impact on you. They don't contact you as carer or nom person as instructed in the legislation and when you ask they fob you off saying they didn't have your ph. no. (Bullshit) or they are too busy to worry about that and then whinge how govt didn't increase their funding when legislation changed. Its been 18 months since new legislation and things have NOT changed. So something that is hard and traumatic becomes even harder, they cause more suffering and frustration”

The next question asked about non-mental health services that the carer coordinated and/or interacted with such as education, legal, housing and Centrelink. Of the 43 respondents only 6 responded that they didn't have involvement with any services. 15 of the respondents had needed to interact with legal services, including legal aid, ACAT and Public Trustees. 9 were involved in the person they care for's NDIS plan. Centrelink was the commonly mentioned by 19 respondents and housing and education system were also mentioned often.

When asked for their best experiences of interacting with these services five carers mentioned that their interaction with the education system had been very positive and responsive. Other responses were highly dependent on individuals within services and did not seem to be consistent experiences across organisations. Carers ACT was mentioned twice.

In regards to their worst experiences engaging with these services, NDIS, housing and Centrelink were all common themes. Ten responded with no comment and 4 chose not to respond. Two responded with ACT Health services again and two had had negative experiences working with education, one specifically mentioned CITs college program. Centrelink was mentioned three times.

The following question asked people about why they had not interacted with services if they had answered no previously. The following data has been cleaned with multiple responses in Other that were NA. These were removed to ensure the accuracy of percentages.

Answer Choices	Responses	Percentage
The person I cared for was well enough to not need them	6	31.58
Someone else handles that aspect of caring	0	
I am not currently caring for them	0	
I chose not to – I want them to be independent as much as possible	1	5.26
I am excluded – the person I care for doesn't want me involved	3	15.79
I am excluded – the person I care for doesn't mind me	5	26.32

being involved, but the services don't facilitate that		
Other	4	21.05

Figure 6: Table of responses for question 13



Figure 14: Responses from question 13 in bar graph

In Other, comments they were retained following cleaning included that the carer was balancing many priorities, including parenting and working so struggled with time to interact with the services the person they cared for needed. Some also commented on the lack of services that were suitable, especially in the Alcohol and Drug addiction space.

	I HAVE NOT EXPERIENCED THIS IN THE LAST 2 YEARS	I HAVE EXPERIENCED THIS OCCASIONALLY IN THE LAST 2 YEARS	I HAVE EXPERIENCED THIS APPROXIMATELY HALF THE TIME IN THE LAST 2 YEARS	I HAVE EXPERIENCED THIS MORE OFTEN THAN NOT IN THE LAST 2 YEARS	I HAVE EXPERIENCED THIS CONSISTENTLY IN THE LAST 2 YEARS	WEIGHTED AVERAGE
<i>Carers are actively included as partners in care for the person they care for</i>	11	12	8	5	8	2.70
<i>Carers are contacted when a person they care for is admitted</i>	32	2	2	0	7	1.79
<i>Carers are informed with appropriate notice regarding discharge from a hospital</i>	29	5	1	1	7	1.88
<i>Carers are actively encouraged to seek help for themselves</i>	20	14	5	2	4	2.02
<i>Carers needs and wellbeing are factored in when deciding treatment plans</i>	32	3	6	0	3	1.61
<i>Carers feel respected and heard by services they interact with</i>	12	17	7	4	4	2.34
<i>Carers feel respected and heard by clinicians they interact with</i>	16	9	8	9	3	2.42
<i>Carers feel they have a choice in when, what and how much care they can provide</i>	26	10	4	3	2	1.78

Figure 15: Table of results from Question 14– weighted averages have been calculated to give a ‘score’ out of 5 on each statement. Higher scores mean more carers reported more positively about their experiences.

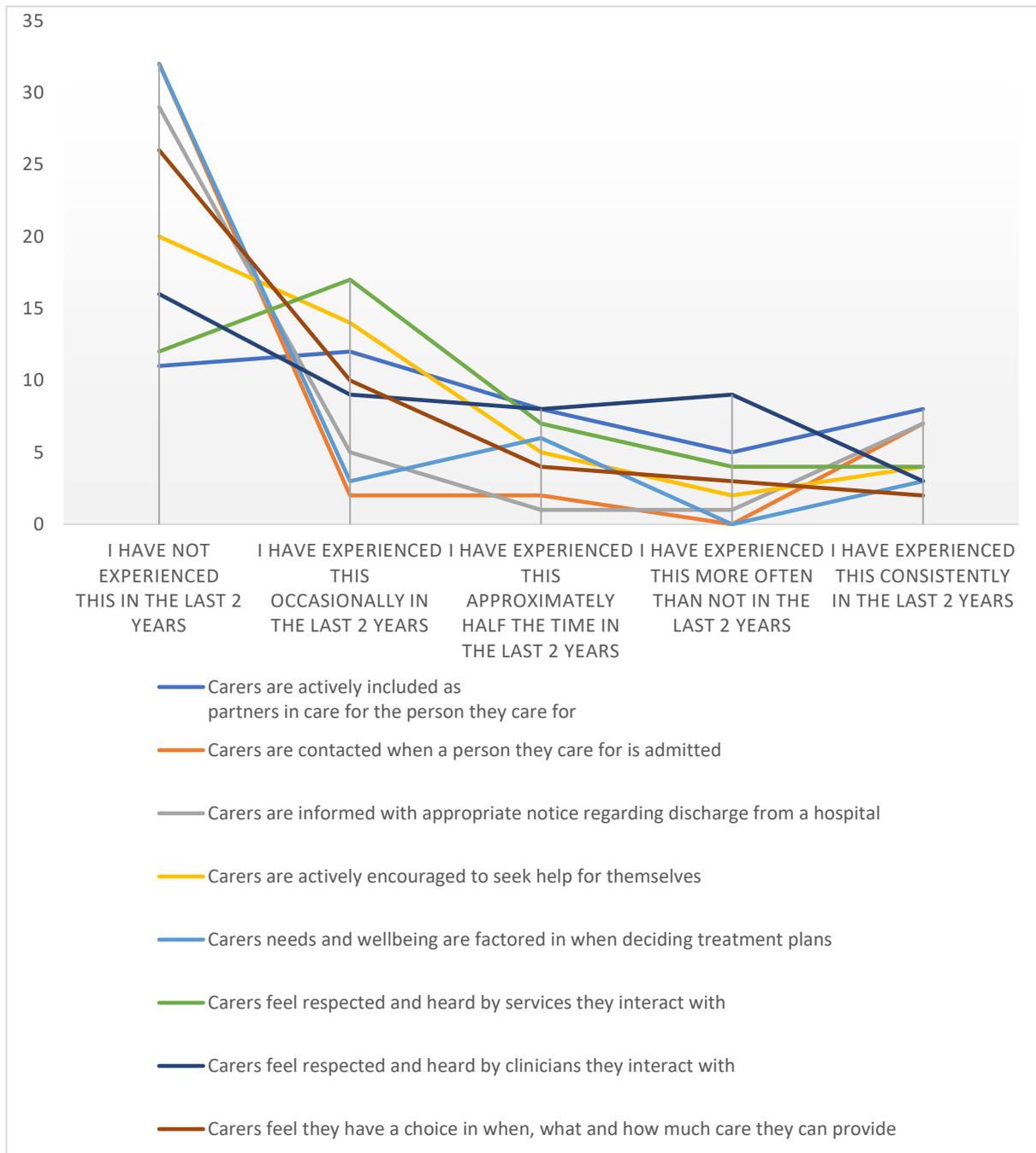


Figure 16: Graph of responses from question 14, with clear trends of more carers' experiences being not in line with the comments.

	I PERCEIVE THAT THIS HAS BEEN A PROBLEM FOR CARERS AND CONTINUES TO BE A PROBLEM (1)	I PERCEIVE THAT THIS HAS BEEN A PROBLEM FOR CARERS IN THE PAST AND IT IS GETTING BETTER (5)	I PERCEIVE THAT THIS HAS BEEN A PROBLEM FOR CARERS AND IT IS GETTING WORSE (1)	I PERCEIVE THAT THIS IS HAPPENING REGULARLY IN THE ACT, I'M NOT SURE OF THE PAST (5)	I PERCEIVE THAT THIS IS NOT HAPPENING REGULARLY IN THE ACT, I'M NOT SURE OF THE PAST (1)	Weighted Average
Carers are actively included as partners in care for the person they care for	24	6	2	4	7	1.93
Carers are contacted when a person they care for is admitted	19	7	2	8	4	2.5
Carers are informed with appropriate notice regarding discharge from a hospital	17	7	3	10	3	2.7
Carers are actively encouraged to seek help for themselves	23	10	1	7	2	2.58
Carers needs and wellbeing are factored in when deciding treatment plans	27	5	2	2	5	1.68
Carers feel respected and heard by services they interact with	17	15	0	6	2	3.1
Carers feel they have a choice in when, what and how much care they can provide	30	1	2	2	6	1.29

Figure 17: Responses to question 15, weighted average was calculated with positive responses rated 5 and negative responses as 1.

Participants were then asked in Question 16, *reflecting on your experiences in the ACT, what three areas are a priority for you to improve? Be as general or specific as you like.*

The responses to this were detailed and varied, these were then grouped, and several consistent themes emerged;

1. Increased quantity and quality of Mental Health Services
2. Improved awareness and decreased stigma in non-mental health services about mental health and caring
3. Carers need to be included, respected and supported in their role
4. Prioritising wellbeing through early intervention and care coordination to create mentally healthy communities

Underneath these was greater detail and specificity regarding not only what that would look like but also some ideas regarding how it could be achieved.

The most consistent comment was that carers needed to be included as partners in care with doctors and services. Nine respondents mentioned this, four talked about improved carer recognition and identification by services and six said that carer supports were invaluable. There were five who identified a multitude of issues with the NDIS, especially the lack of mental health awareness with workers. Increased services and accommodation options for adolescents/young adults was also a priority.

It was suggested that The Mental Health Act 2015, the Office for Mental Health and also the Recovery College could be instrumental in progressing these improvements.

In the final question, we allowed participants to make any further comments; the following issues emerged that had not been addressed in previous sections.

“The big general issue from my experience is how to get the health care system involved when the person with the mental health issue does not want help”

“I’m lucky to be a qualified psychologist myself which helps enormously (and is proving more important for helping our son as he becomes more aware of things) but it troubles me that other mental health carers are at risk of their own mental health issues without more support when they know things are worsening. It’s so much harder to manage things when a crisis occurs and easier to tackle what needs to be done as a preventative measure.”

“My experience has generally been good. There does seem to be good support available, and I really hope that people are informed of this at the beginning now. I do think things have improved.”

“I have waited all my adult life for something better for sufferers and their supporters. Things have got worse.”

Discussion

This survey aimed to evidence systemic issues facing mental health carers in the ACT and to also allow carers to reflect on what their priorities are for the future. As the peak body for mental health carers in the ACT, we regularly communicate with carers about issues they are seeing in mental health services. This survey was taking a broader look at being a mental health carer in Canberra and focusing on their needs and wellbeing holistically.

The first three questions examined that experience of being a carer, whether they felt recognised and understood for their role and whether they had experienced stigma because of it. Findings from the survey showed that carers had diverse experiences and opinions on how well they were recognised and understood in the community and in the mental health system. Of those surveyed, 60.87% respondents felt that Canberra did not have a good understanding of what a carer is. Only 37.78% of respondents thought that mental health professionals knew what carers are. When asked whether they thought there was stigma associated with being a mental health carer, 71.74% responded affirmatively.

This demonstrates the continued need for awareness raising activities and improvement in engaging all sectors on the role of mental health carers. It is concerning that even within the mental health space the term carer was not seen to be well understood. Highly concerning that stigma remains an issue for carer, this is also an area where more work is needed, especially in considering the vital role mental health carers play in our communities and across Australia.

In 2016, it was estimated by Mind Australia that mental health carers provide over \$13.2 billion worth of care in Australia every year (Mind Australia, 2016). This was a conservative estimate calculated on the cost of replacement care. However, in understanding the true value of mental health carers it is important to note that they have uniquely specialised and compassionate care for their loved one. They are experts in the person they care for's condition and the inclusion of carers can greatly improve outcomes for both patient and carer (Brady et al. 2016). Not only this but the impact of caring on mental health carers can be profound. More mental health carers experience high levels of anxiety, depression and stress than other carers and they are more likely to neglect their own health and wellbeing to support their loved one (Berk & Berk 2015).

Despite this, carers continuously report feeling underappreciated, excluded and disrespected by mental health services they engage with and more broadly across the community.

In the questions in this survey regarding help seeking amongst carers it was positive to see that many carers had accessed supports for themselves and had found that beneficial. There is strong demand for the carer support services for mental health carers and the comments were demonstrative that carers felt the help they received had supported their wellbeing and their ability to continue caring. Research is frequently undertaken to measure the types of interventions that improve carers' wellbeing and ability to care. In research conducted Brady et al. (2016) they found that within the mental health service context Family Psycho-Education (FPE) was part of optimal treatment for psychotic disorders and improved outcomes for both patients and carers. This was also demonstrated in a systematic review undertaken by Yesufu-Udenchuku et al. (2015) where evidence was also supportive of the impact support groups had for carers wellbeing.

In this survey, of those who reported having used supports two consistent themes emerged. Firstly that they had needed to be pushed to get help for themselves and/or it had taken them a while to accept help and also that they wanted to know how to better support the person they cared for. Respite, counselling, advocacy and education all came through as valuable supports. Reasons that carers provided for not seeking support for themselves included lack of time, feeling like they were coping well and that other people may need it more and feeling that the services were unable to help them and/or having had previous negative experiences.

Most participants who responded to the survey had recent experiences navigating mental health service with 80.4% having interactions within the last 18 months. There was also a wide variety of mental health services mentioned, with most respondents having engaged with the public community mental health services and the hospitals.

In the next section carers were asked to reflect on their best and worst experiences of mental health services to try to explore what made a service experience good or bad for carers. Consistently it was reported that good services communicated with them, included them where they could, made them feel heard and understood what they were going through. There was also comments that more related to accessibility and continuity of care for the person they cared for.

Comments included *'they took the time out to listen to me also'*. Another stated the *'School Psychologist was very helpful and freely gave of her time'*

One carer stated they found the ambulance officer to be most supportive *'I felt supported. The ambulance officer said he wouldn't abandon me until we got the help we needed for our daughter'*.

The following questions were asking carers to reflect on their worst experiences within mental health services.

Of the 43 respondents to this question 11 did not have a negative experience to comment on. That is, of the 43 respondents more than 25% did not have a 'worst' experience. Comments included *"No real issues"*, *"Both excellent"* and *"Neither are bad services - both have been wonderful in the support they have provided when required"*. These respondents had utilised services through Carers ACT, Canberra Rape Crisis Centre, Calvary Older Persons Health Service, The Adult Mental Health Unit and a Community Mental Health Treatment Team (unspecified). Northside Psychology and GPs were also mentioned positively.

In voluntary surveys, such as this, there is a tendency for disproportionately large percentages of negative experiences because people who have negative experiences are often more prone to provide feedback. It is therefore sometimes difficult to know how representative the sample is of general carer experiences. Extrapolated based on census data of mental health carers and ACT population figures, it is estimated that there are approximately 3700 primary mental health carers in the ACT. Our sample size was therefore relatively small to analyse the significance of this response. However, we can say that asking this question to all mental health carers in the ACT we would expect (95% CI) between 62.56% and 87.44% of carers to respond with a 'worst' experience, which remains most carers in the ACT.

When asked about specific services, CAMHS was mentioned as being the 'worst' for four respondents, this was every respondent who had reported interacting with the service. See results section for participant comments. There were themes of CAMHS not working with carers on understanding severity of mental illnesses and carers feeling ill-equipped and unsupported to care for their children between appointments.

Tuggeranong Mental Health and Woden Mental health were mentioned each once. The hospitals, both Calvary and Canberra Hospital were mentioned multiple time, largely comments about difficulties in the Emergency Departments,

"Emergency Department at Calvary. The mental health nurse conducting triage was very dismissive of concerns expressed by both myself and the care recipient and was pressuring the psychiatric registrar to send us home, during a very dangerous period."

There were several mentions of the CAT team however, with recent changes to the structure of the Adult Community Mental Health Service Model of Care it will be valuable to review this going forward to see whether the new services are better in their engagement with carers. It would also be valuable that these services review the comments in the results section of this paper to see what concerns had been previously regarding service engagement. Consistent themes from carers included being ignored by services, unable to get the supports for the person they needed, not having illness explained, feeling like the level of risk was not adequately handled and feeling disrespected.

The results of this survey are affirming that one of the fundamental delineating factors between a good and bad carer service experience is communication. Communication that is respectful, listens and takes on information from the carer, explains the illness and the decision making well and supports the carers needs going forward is a marker for good service.

In regards to the results on carers experience of interacting with other services as part of their caring role it was more difficult to obtain patterns or themes of services that were consistently good or difficult for carers. Of interest were how many carers had engaged with the legal system, Centrelink and the education system. Of the 43 responses, 34.9% had interacted with legal services, 44.2% had interacted with Centrelink and 37.2% had interacted with education. It was clear from the responses that these are common areas of frustration where carers feel uninformed, had difficulty in navigating the systems and getting what they needed. Although there were more positive comments regarding school engagement than with legal or Centrelink.

It is common to hear that carer inclusion is not possible in health and community services due to the care recipient not wanting their carer involved or concerns around patient confidentiality. Some carers have reported this to Carers ACT previously and it was an important issue to interrogate. Therefore, following the questions regarding interacting with services, the carers who were not involved were asked to provide feedback on why they were not involved. Interestingly of the 19 people who responded to this question, only 15.79% said that they had not been involved because the person they care for does not want them involved. This compares to 26.32% who reported that the person they cared for does not mind them being involved but that the service did not facilitate this. It is a difficult arena for staff in these services, especially in negotiating with people who may have diminished decision making capacity when they are in treatment. However, having this information there is clearly scope for more proactive practice of engaging with carers in services.

In the last sections of the survey, carers were asked to respond to a series of statements firstly with their recent experience of those statements and then with what they perceived to be the general carer experience. In determining priorities going forward it was crucial that they were based on current experiences as much as possible and that the 'hearsay' component of negative experiences could be reduced. It has also demonstrated some interesting comparisons between what people perceive to be happening in mental health and what is happening in practice.

In looking at their own experience, carers generally identified positively at being included as a partner in care, weighted average of 2.7 of 5. Of greatest concern was when responding to "*Carers needs, and wellbeing are factored in when deciding treatment plans*" this scored a weighted average of 1.61 of 5. 32 respondents of 44 responded that they had never experienced this in the last 18 months. When considering how vital the carer can be in improving treatment outcomes and how impacted they can be from their caring role this seems highly concerning.

In examining their perceptions of the mental health carer experience, overall there was a slightly more positive perception of the carer experience than reported in the previous question. This was especially true of contact with hospitals on admission and discharge and carers being encouraged to seek help. In contrast to this was the Carers are actively included as partners in care for the people they care for which people perceived was not happening often.

We can infer from this information that carers are not having their perception of the system broadly negatively skewed by a single repeated story or even by their own experiences. If anything, the perception of the broader experience is more positive than the experiences carers are reporting for themselves.

In the final question, carers were asked, *reflecting on your experiences in the ACT, what three areas are a priority for you to improve? Be as general or specific as you like.*

The responses to this were detailed and varied, however several consistent themes emerged;

1. Increased quantity and quality of Mental Health Services
2. Improved awareness and decreased stigma in non-mental health services about mental health and caring

3. Carers need to be included, respected and supported in their role
4. Prioritising wellbeing through early intervention and care coordination to create mentally healthy communities

This is interesting within the context of current consultations being undertaken in the ACT, including those on the Office for Mental Health and Wellbeing which has reported similar themes. It is especially interesting that we are hearing consistently that carers are focused on wellbeing and early intervention.

In other feedback we have received carer report feeling this has been lost since the NDIS psychosocial disability funding came in, that finding services was more difficult, especially if the person they cared for was 'too well' to access the NDIS. Also, the process of proving psychosocial disability and fighting for funding at plan reviews to keep supports has been highly traumatic and does not help to maintain wellbeing.

Whilst this survey has offered a great deal to discuss, it also will be an interesting process to repeat following some of the alterations in the sector being more fully established and to measure if there is improvement for mental health carers in these areas.