



Filling the Cup Back Up

2022 ACT Mental Health Carers Survey Report

JUNE 2022

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EXECUTIVE SUMMARY

The title of this report uses a quote found in one of the responses by a carer in the 2021 survey – “*I recognise that caring exhausts a person, both physically and mentally, and that a carer needs to take action **to fill their cup back up**. As well as talk to other carers and support people about how to manage the stress caring causes.*” This quote has been used to recognise that carers deserve support to continue their caring role and ‘fill their cup back up’ when they are feeling burdened. By identifying and improving service experiences, the findings of this report endeavours to assist in filling the cup.

The results of the survey captured useful information about access to services, positive and negative experiences with individual services and the ACT mental health system as whole and will guide the work of Mental Health Carers Voice going forward.

Several priorities from the 2018 and 2020 surveys continued to be issues in the 2021 survey. The results of the 2021 survey can be grouped under the following themes:

1. Discrimination and Understanding
2. Safety and Wellbeing
3. Access and Inclusion

The results regarding the perception of whether carers were experiencing discrimination in the ACT community indicated a noticeable decrease from the previous years. Unfortunately, these improvements in perception have not translated over to the self-reported experiences of discrimination. Likewise, safety remains a significant area of concern as almost half of carers report feeling unsafe in their caring role within the last 18 months. Additionally, carers have sought support increasingly over the last two surveys. Nonetheless, this also raises the concern of increasing carer burden. The survey results raise multiple concerns regarding access and inclusion, particularly flagging barriers to accessing mental health services. Results found that carers have only experienced inclusion, respect, and communication in their interactions with mental health services occasionally or approximately half the time in the last 2 years. Whilst having slightly improved from previous years, these results remain concerningly low.

The primary areas of improvement highlighted by mental health carers in the 2021 survey were:

1. Carer Inclusion in Mental Health Services
2. Service Quantity and Quality
3. Carers Support (separate to mental health services)

Although the results demonstrate slight improvement in certain areas, it is evident that further research, advocacy, and policy work is required to ensure that carers are provided a robust and inclusive mental health system in the years to come.

METHODOLOGY

The survey was a descriptive design using a mixture of qualitative and quantitative research questions with a mixture of open-ended and close-ended questions. Questions were adapted from the 2018 Priorities survey in collaboration with the Mental Health Carers Voice Advocacy and Policy Advisory Group to ensure their suitability and relevance.

Participants were recruited within the ACT through the mental health carers voice newsletter, social media and sharing with partner organisations. Entering a draw for six gift vouchers was offered as an incentive for completing the survey. The sampling was then voluntary and targeted at current mental health carers, though former carers and carers who were also care recipients could identify themselves if they chose to participate. The survey was completed online using Microsoft Forms.

Similar to the 2020 survey, due to the 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

Demographics

113 carers responded to the 2021 survey.

Questions 1-7 focused on demographic information about carers answering the survey.

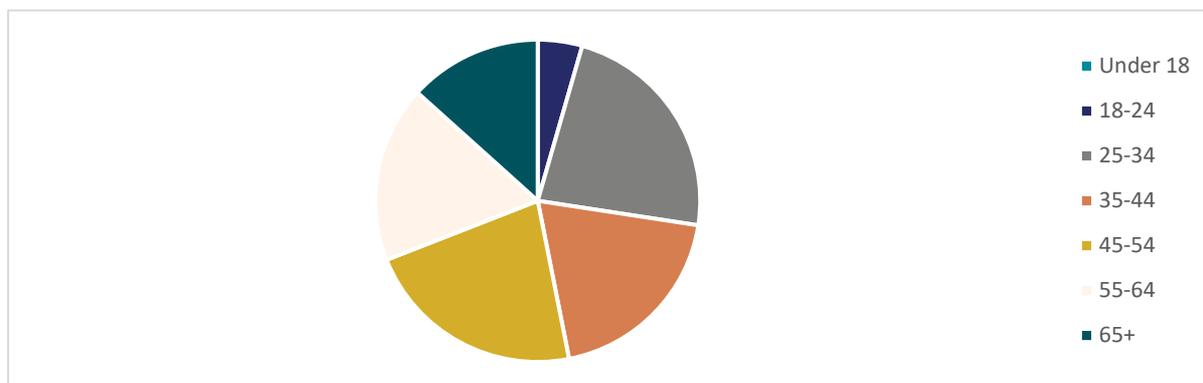


Figure 1: Age of Survey Respondents

Other Key Demographics:

- 72% of the respondents identified as women, 27% of the respondents identified as men, 1% person identified as non-binary and 1% person preferred not to disclose.
- 39% of the respondents identified as Aboriginal or Torres Strait Islander and 4% preferred not to say.
- 32% of the respondents identified as LGBTQIA+, 10% of the respondents preferred not to disclose this information.
- 25% respondents spoke a language other than English at home and 5% of the Respondents preferred not to say.

The types of mental health conditions or illnesses care recipients are living with is shown in figure 2 below. There was a total of 267 responses to this question, noting that several care recipients experienced multiple mental illnesses. The largest proportion of people were living with anxiety disorders. This is not consistent with the results from previous surveys where equal proportions of respondents selected Mood disorder and anxiety disorder.

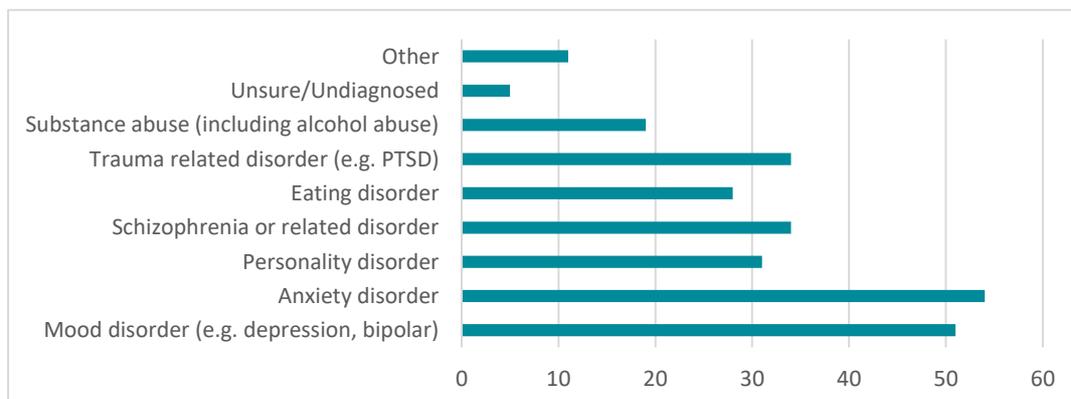


Figure 2: Mental Illness experienced by Care Recipients

Respondents who selected 'other' provided the following answers:

- "Alzheimer's Disease".
- "OCD turned into psychiatric".
- "Severely Depressed".
- "Tremor Dystonia".
- "Autism and various physical issues".
- "Various Physical Issues' and 'a number physical issues"; and
- "ADHD".

The data in Table 1 was in relation Question 7, which asked in what capacity carers were completing this survey. Answers indicated a majority of the respondents were currently in a caring role for someone with a mental illness. Further, results indicate 22 respondents were carers for someone with a mental illness in the past. The respondent who selected 'Other' stated, 'and physical', but failed to indicate which category it related to, leaving ambiguity to their response.

Capacity in which the respondent is completing this survey	Count
I am currently caring for someone with mental ill health	53
I have been a carer for someone with mental ill health in the past	21
I am a mental health consumer and a mental health carer	22
I share caring responsibility for someone with mental ill health	16
Other	1

Table 1: Capacity in which the respondent completing this survey

Discrimination and Safety

Respondents were asked whether there was a perception that carers experienced discrimination in the community due to their caring role. Respondents were asked to select either 'Yes', 'No', 'Unsure' or to provide a text answer.

The data indicated that 36% of carers responded that there was a perception of experienced discrimination, 33% indicated they didn't have this perception and 31% were unsure (Figure 3). When comparing the same question from the 2020 survey, 54% of carers agreed with the statement, 25% didn't, and 15% were unsure.

Further, respondents were asked if they had personally experienced discrimination due to their caring role. The data indicated that 36% reported having experienced discrimination, 49% said they had not, and 15% said they were unsure (Figure 4). This data has remained consistent with the results from the same question in the 2020 survey.

What these results demonstrate is a noticeable decrease in the perception of discrimination against other carers in the community over the last year with the bulk of responses shifting to an area of being unsure rather than agreeing with the concept of perceived discrimination.

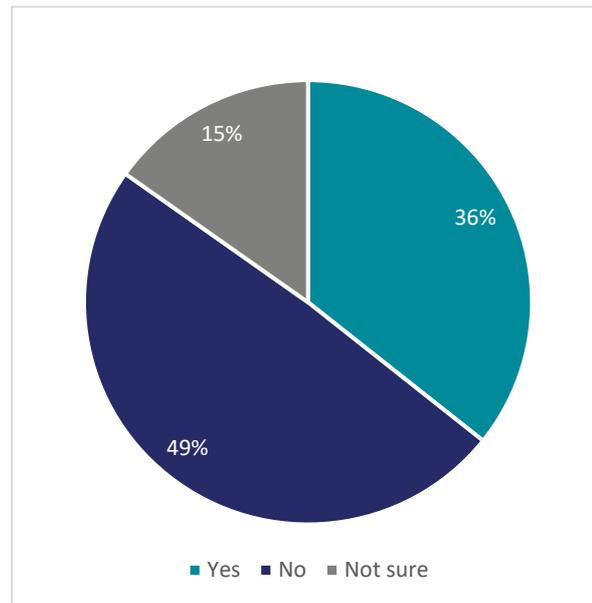
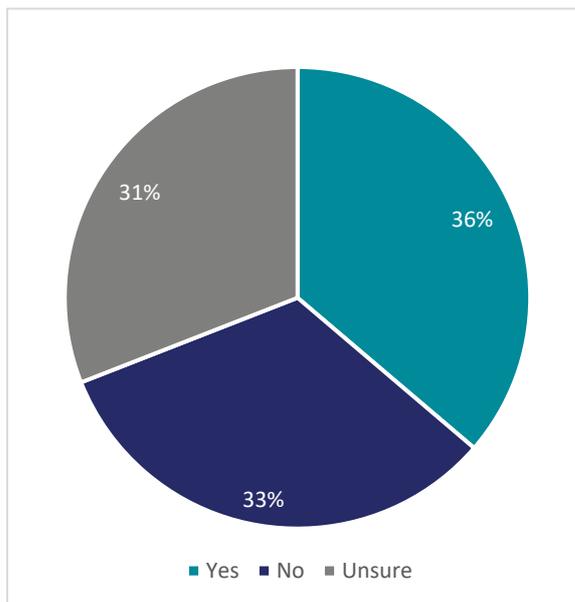


Figure 3: Perception of Discrimination in Community **Figure 4: Personal Experience of Discrimination**

Respondents were asked if over the last 18 months they had felt unsafe in their caring role. The data indicates that 49% of carers report that they felt unsafe. One carer shared a personal story outlining how their experiences varied between caring for their mother and father. A second carer pointed out that they only felt unsafe due to the toll that caring took on their health. When compared to the 2020 survey result for this question, feeling of safety or the lack thereof are more equally divided. No obvious connection could be found between feeling unsafe and age, gender, access to supports or the mental health diagnosis of the care recipient.

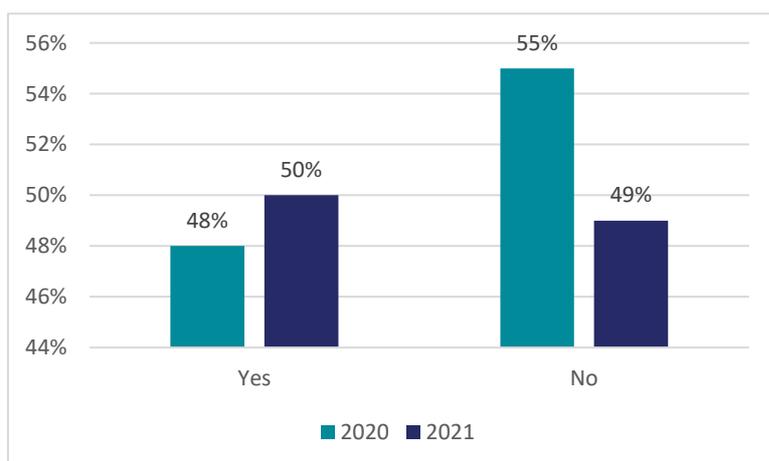


Figure 5: Comparison of Respondents who felt unsafe in their caring role over the last 18 months

Carers in the Community

Question 8 and 11 asked the respondent about their perception of carers generally by the local community and specifically by mental health professionals. Results from Figures 6 and 7 demonstrated that carers felt that levels of understanding were generally low to average for both groups, with mental health professionals having a slightly better understanding. An improvement has been observed in understanding by both groups when compared to the results of last year, with a greater number of carers reporting high understanding and less reporting none to average.

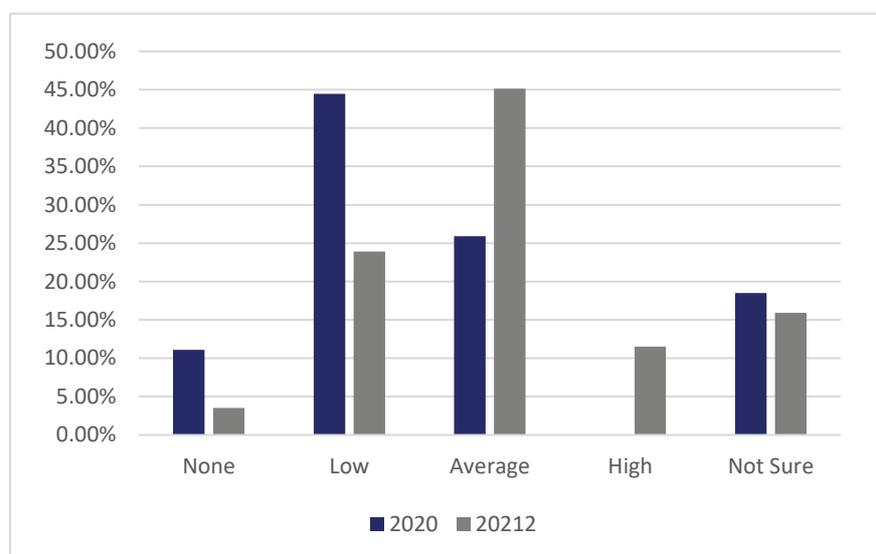


Figure 6: Comparison of understanding of Carers by the Canberra Community

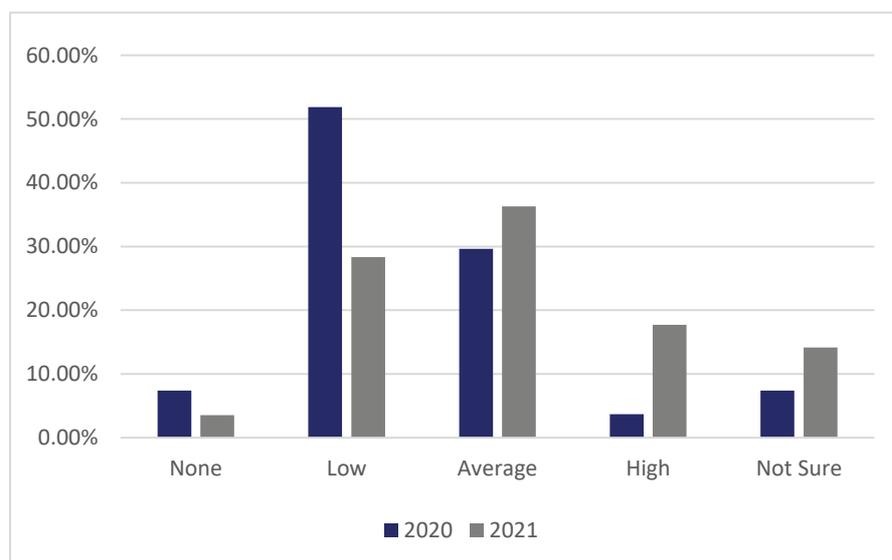


Figure 7: Comparison of understanding of Carers by Mental Health Professionals

Respondents were asked if they had sought supports such as counselling, support groups, training, or respite as a mental health carer. The results indicate that 87% of carers said they had sought supports, 10% said they had not, and 4% carers were unsure. The results demonstrate a steady increase in mental health carers accessing supports for themselves over the last two surveys.

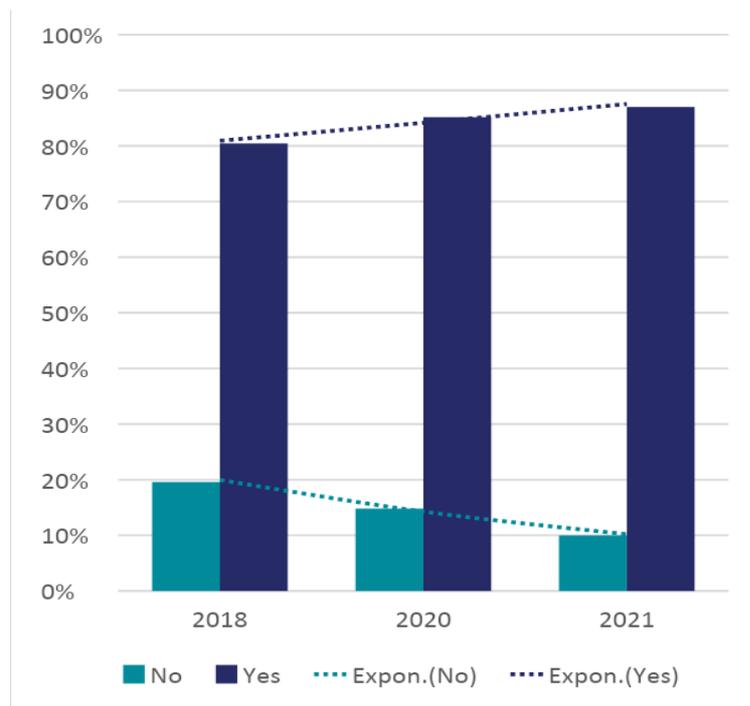


Figure 8: Comparison of carers self-reported access to supports

Respondents were given the opportunity to provide a detailed response as to why they had or had not accessed these supports. A total of 58 responses were received.

Of the carers that said that they have accessed supports in the last 18 months, several mentioned that they were doing so because they felt overwhelmed or were struggling to cope in their caring role. A carer pointed out that *“the pressure and drain of caring can be immense.”* Others stated that they accessed supports because they needed further education on how to best care for their own mental health, as well as the care recipient. Carers also accessed these supports because some found that their caring role could be *“incredibly lonely and discouraging”*. Another response encapsulating the need for companionship in the caring journey: *“I need to feel that others understand what I am living through and to sustain hope that I will survive...”*

The carers who had not accessed supports in the last 18 months provided responses such as:

- *“There is no need to”*
- *“Couldn’t access as read zoom/teams and internet access”*
- *“Difficult to find time and appropriate support”*
- *“Was not sure that it would help”*
- *“I wasn’t sure if this was available, or if I was eligible”*

Experience of Services

Carers were asked which services they had interacted with as part of the mental health system over the past 18 months. Table 2 provides an overview of the mental health services interacted with each year. Where a service was also mentioned in the 2018 survey, it has been included.

Service	% of 2021 Responses	% of 2020 Responses	% of 2018 Responses
Adult Mental Health Unit (AMHU)	5%	3%	15%
Calvary Ward 2N	0%	1%	13%
Community Mental Health Centre	11%	7%	28%
Counsellor	8%	9%	
Dhulwa Mental Health Unit	2%	1%	
Forensic Mental Health Services	1%	1%	
GP	14%	19%	11%
HAART Team	3%	5%	11% (as CAAT Team)
Hyson Green	2%	2%	4%
Older Persons Mental Health Unit	3%	1%	2%
Other	5%	8%	
Private Psychiatrist	10%	9%	
Private Psychologist	12%	12%	4%
Public Psychiatrist	9%	9%	
Public Psychologist	7%	9%	13%
School Psychologist	6%	4%	
Step Up Step Down	1%	2%	
The Cottage Adolescent Day Program	1%	1%	

Table 2: *Mental health services accessed by year*

The majority of the respondents indicated that they had accessed multiple services, with the top 3 services being: GPs, Private Psychologists, and the Community Mental Health Centre. This data is consistent with last year, whereby GPs and Private Psychologists were within the top 3 services used. However, in this year's data, the Community Mental Health Centre came within the top 3 services accessed, which was consistent with the 2018 survey results. Private and Public Psychologists and Psychiatrists have continued to be among the most accessed mental health services. Of the respondents in this year's survey, most had accessed Private Psychologists and Psychiatrists as opposed to their public counterparts.

Other Services/Programs Accessed

- Occupational Therapist
- TMS Technician
- UCH Rehab Ward
- Canberra Rape Crisis
- ACT Drug and Alcohol services
- Child and Adolescent Mental Health Services
- Blue Knot Foundation
- ACT Police Liaison Unit
- Victims Assistance Counselling
- Calvary Private Specialist
- Claire Holland House

Respondents were asked which of these services were most helpful to carers. Of the 79 responses to received, 22 carers mentioned Psychologists, 12 mentioned the GP and 9 mentioned Psychiatrists. Other services mentioned included counsellors, Community Mental Health Centres, and CAMHS. When asked to comment on why, common themes arose including the ability for these services to foster an ongoing relationship with both the carer and care recipient, being able to monitor medications, and being well-informed.

Respondents were asked which services were least helpful which received 70 responses. The following services were most frequently mentioned: Psychiatrist (8), Psychologist (7), School Psychologist (6), and GP (6). Themes arising from the comments included poor communication with carers, a lack of understanding of the complexities of mental health, long waiting times or lack of capacity to see care recipients and not listening to carer concerns.

Additionally, respondents were asked if they were required to travel interstate for their care recipient to access these mental health services over the last 18 months. Of the responses, 34% of carers (38) indicated that they had travelled interstate, and 65% (73) said they did not. One respondent indicated it was not applicable to them and another respondent reported that they had trouble accessing the services in the ACT, due to both inadequate financial accessibility and limited capacity amidst psychiatrists in the territory. Carers accessing interstate mental health services for their care recipients has increased slightly since the last survey reporting 29.63%.

Carers were asked about why they did not coordinate or interact with services with 33% (29) responding 'I chose not to – I want them to be independent as much as possible' 26% (23) with 'The person I cared for was well enough to not need them, 23% (20) said 'I am excluded – the person I care for doesn't mind me being involved, but the services don't facilitate that' and 17% (15) said 'I am excluded – the person I care for doesn't want me involved'.

Respondents were asked about non-mental health services that the carer coordinated and/or interacted with such as housing, legal, education and Centrelink. Of the responses, 77 answered this question. Of the other services that mental health carers have needed to interact with, Centrelink was mentioned 25 times, followed by Housing services (20), Educational intuitions (19), Legal services (18), and NDIS (15).

The most useful of the aforementioned other services included a wide variety of responses. Services that were considered useful included Educational Institutions (9) for disseminating information,

Housing (6) and Centrelink (4), both more so for providing housing and income as opposed to providing quality service, and Carers ACT (3) for providing support programs. Nonetheless, it was most commonly indicated that no services were found to be useful for carers (this was mentioned 10 times). A number of responses indicated that quality of interaction varies hugely depending on the individuals involved.

When asked what the least useful of the services were, some of the 67 responses included the NDIS (9), Housing (9), and Centrelink (9). This was largely due to recurring themes regarding service quality, such as the lack of follow up, overcomplication, delay in service, or being too time consuming.

Carer Inclusion, Respect and Communication in Services

Questions 23 and 24 asked carers to complete a matrix of answers against statements about carer engagement with services. These questions examined the following statements:

- *Carers are actively included as partners in care for the person they care for*
- *Carers are contacted when a person they care for is admitted*
- *Carers are informed with appropriate notice regarding discharge from a hospital*
- *Carers are actively encouraged to seek help for themselves*
- *Carers needs and wellbeing are factored in when deciding treatment plans*
- *Carers feel respected and heard by services they interact with*
- *Carers feel respected and heard by clinicians they interact with (Q23 only)*
- *Carers feel they have a choice in when, what and how much care they can provide*

Question 23 focused on their personal experience over the past 2 years, asking respondents to indicate their experience along a Likert scale. A Likert scale is a rating scale to express opinions, attitudes, and behaviours.¹ The question required respondents to rank their experiences by selecting the following options:

- *'I have not experienced this in the last 2 years' = 1*
- *'I have experienced this occasionally in the last 2 years' = 2*
- *'I have experienced this approximately half the time in the last 2 years' = 3*
- *'I have experienced this more often than not in the last 2 years' = 4*
- *'I have experienced this consistently in the last 2 years' = 5*

Each of the above options have been allocated a nominal value to assist with interpreting and analysing the data from Question 23.

Table 3 below provides the median (Mdn), which is used to measure the central tendency of the ordinal data provided by the Likert scale. In simple terms, this is what the 'average' respondent might think or be the 'likeliest' response.²

¹ Geoff Norman, "Likert scales, levels of measurement and the "laws" of statistics," *Advances in Health Sciences Education* 15, no. 5 (2010): 629.

² See Achilleas Kostoulas, "On Likert scales, ordinal data and mean values," *Applied Linguistics & Language Teacher Education* (blog), February 13, 2013, <https://achilleaskostoulas.com/2013/02/13/on-likert-scales-ordinal-data-and-mean-values/>; Achilleas Kostoulas, "How to interpret ordinal data," *Applied Linguistics &*

Results indicate that respondents have only experienced inclusion, respect, and communication with mental health services occasionally or approximately half the time in the last 2 years (Mdn=2-3). This is an improvement from the 2020 results, where the central tendency of experience for most statements ranged from not experienced at all (Mdn=1) to experienced only occasionally (Mdn=2). However, there has not been a change in the respondents' experiences with clinicians. The 2021 results indicate that carers have felt respected and heard by clinicians only half the time in the last 2 years, consistent with the results from the 2020 survey (Mdn = 3).

The Inter-Quartile Range (IQR) in Table 3 provides a measure of the spread, which when low (IQR ranging between 1-2.5) indicates consensus amongst respondents.³ The IQR of the 2021 data suggests that the responses were relatively more polarised (IQR=2-3) when compared to the consensus of responses in 2020 (IQR=1). Regardless, the IQR is low enough in both years to indicate that a majority of carers have not been having vastly different experiences of the mental health sector.

Language Teacher Education (blog), February 23, 2014, <https://achilleaskostoulas.com/2014/02/23/how-to-interpret-ordinal-data/>;

³ Ibid

	Data	<i>Carers are actively included as partners in care for the person they care for</i>	<i>Carers are contacted when a person they care for is admitted</i>	<i>Carers are informed with appropriate notice regarding discharge from a hospital</i>	<i>Carers are actively encouraged to seek help for themselves</i>	<i>Carers needs and wellbeing are factored in when deciding treatment plans</i>	<i>Carers feel respected and heard by services they interact with</i>	<i>Carers feel respected and heard by clinicians they interact with</i>	<i>Carers feel they have a choice in when, what and how much care they can provide</i>
2020 Responses	Count of Responses (N)	27	21	22	26	25	25	26	25
	Median (Mdn)	2	1	1	2	1	2	3	1
	Inter-Quartile Range (IQR)	1	1	1	1	1	1	1	1
2021 Responses	Count of Responses (N)	109	102	102	106	106	104	106	101
	Median (Mdn)	3	2	3	3	2	3	3	2
	Inter-Quartile Range (IQR)	2	2.75	3	2	2	2	2	3

Table 3: Data table of Question 23 responses

Question 24 asked respondents about their perception of inclusion, respect, and communication for all carers. To better interpret the data, we have split Question 24 into two parts. The first part looks at carers who had prior experience with the mental health system. (Figure 9A). The second part looks at carers who are not sure of past experiences (Figure 9B).

Figure 9A provides a comparison of the results from the 2020 survey against the results from the 2021 survey in relation to their perception of carers experiences of inclusion, respect, and communication generally. The reason for the comparison is to determine whether services' treatment and attitudes towards carers have improved over time.

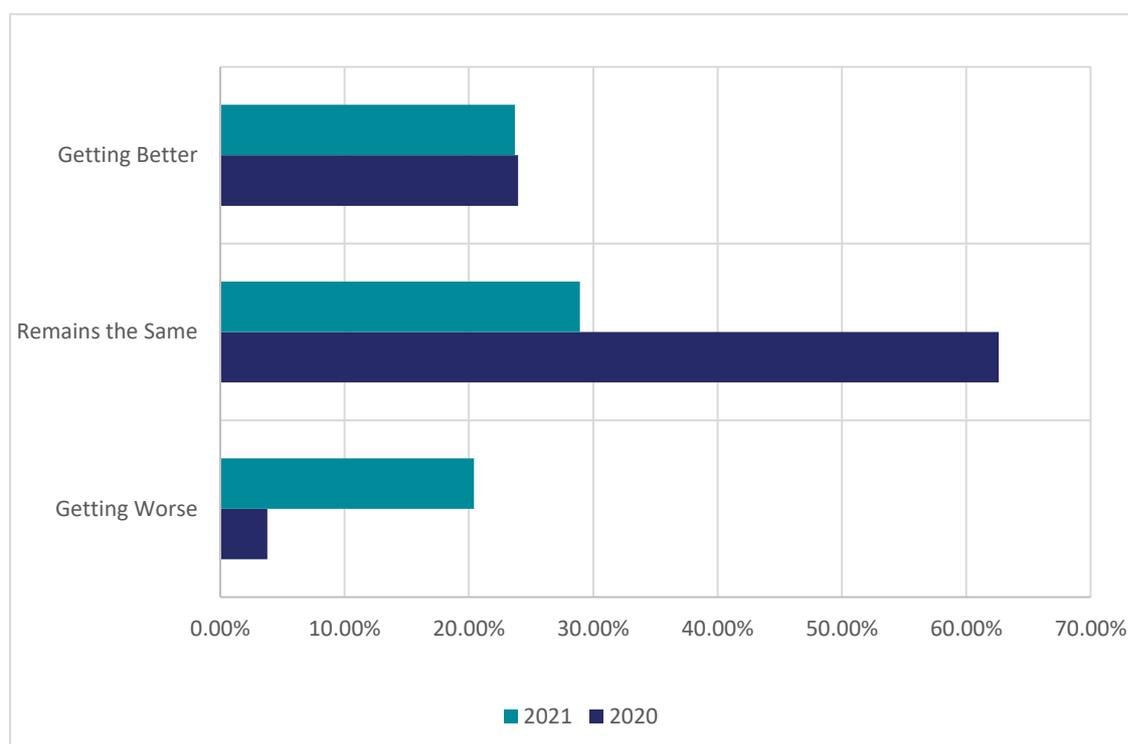


Figure 9A: *General perception of carer experience in the mental health system*

The 2021 results indicate that there was a decrease of carers perceiving that the services were getting better, dropping slightly from the previous year's results. Likewise, there has been an increase of carers perceiving that the services have been getting worse (from an average of 3.78% to 20.40%). Further, a significant number of carers still perceived that the system had remained the same.

Figure 9B provides a comparison of the results from the 2020 survey against the results from the 2021 survey carers who were not sure about past service experiences. The reason for this comparison is to determine the current perceptions of inclusion, respect and communication from carers who are new to the mental health system in the ACT in a specific year.

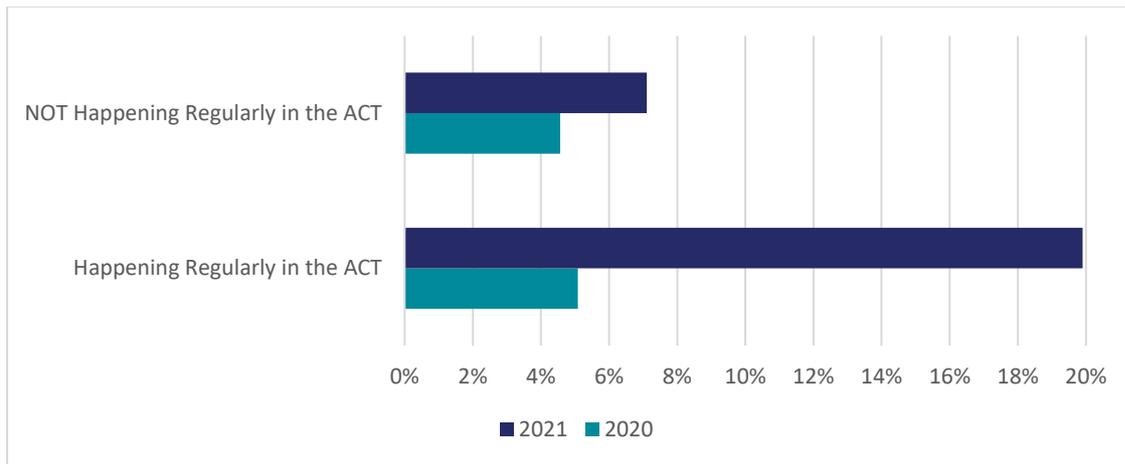


Figure 9B: Carers who are not sure about past experiences and their perception about inclusion, respect, and communication from services.

The results indicate that on average 19.9% of carers perceive that inclusion, respect and communication is happening regularly in the ACT. In contrast, on average 7.11% of carers perceive that inclusion, respect and communication is not happening regularly in the ACT. This contrast is starkly different to the 2020 results, whereby there was almost an equal number of carers that perceived inclusion, respect and communication was happening and not happening regularly in the ACT.

Areas for Improvement

Carers were asked to reflect on their experiences and nominate 3 areas for improvement. These were analysed to find the most common themes mentioned by the respondents overall.

Theme	No. of responses	% of responses
Carer Inclusion/Support in Mental Health Services	30	26.5%
Access to NDIS	4	3.5%
Continuity/integration of services	3	2.7%
Service Quality	11	9.7%
Service Quantity	19	16.8%
Carer Support (separate to mental health services)	11	9.7%
Youth Mental Health including <ul style="list-style-type: none"> - School age - Transition to adult services 	8	7.1%
Assisting financial/housing burden	7	6.2%
Employer awareness of carers	2	1.8%

Table 4: Common areas of improvement

The final question of the survey asked carers to comment on any other matters of interest to them. Many of these comments added context to carers' priorities and illustrated the distress and frustration that carers experience.

On mental health services:

"There needs to be a lot more support for mental health consumers"

"We need more resourcing for CAHMS and more free placements in the DBT program"

"Could the Public Mental Health clinics please have continuity of care"

On carer burden and distress:

"I'm exhausted"

"I'm exhausted. Advocating is exhausting, being emotionally available 24/7 is exhausting, there is no time for support for carers..."

"I struggle to care for myself now. Unfortunately, it appears the ACT Government continues to not prioritise health and I don't believe it ever will."

On the Carers Recognition Act 2021 (ACT):

"I am very pleased the Carer Act was passed in ACT"

DISCUSSION

The aim of this survey is to determine whether there has been a significant difference in carers experience of the ACT mental health system over the years. In doing so, this survey looks at previous data, including that of 2018 and 2020. This survey confirmed the issues that we regularly hear about from carers and provided us with insight into their broader needs and wellbeing. The data gathered in this survey will provide an evidence base for future policy and advocacy work within Carers ACT. For the purposes of this discussion, the questions have been categorised into 3 main themes: Discrimination and Understanding, Safety and Wellbeing, and Access and Inclusion.

Discrimination and Understanding

The results regarding the perception of whether carers were experiencing discrimination in the community indicated a noticeable decrease from the previous year (from 54% to 36%). There has likewise been an increase in the proportion of carers who are uncertain about the experiences of discrimination by other carers in the community. The questions regarding community and mental health professional understanding of the carer role can also be considered in this context. Results demonstrate (Figure 6 and 7) that carers are perceiving increasing levels of understanding of their caring role amongst the community and mental health professionals.

This could be due to a slow change in social norms, be it through education or media, which acknowledges the role of carers. The recent passing of the *Carers Recognition Bill 2021* (now the *Carers Recognition Act 2021* (ACT)) and relevant advocacy and policy work being completed in the area may be considered contributory factors. Other dynamics that could account for these changes include:

- An increase in intergroup contact, such that carers are given a platform to incite change (e.g., governance committees) whilst interacting with non-carers.
- A decrease in intergroup contact due to COVID and social isolation, thus limiting the ability to share experiences with other carers.
- A combination of the above or another dynamic not specified here.

Unfortunately, these improvements in perception have not translated over to the personal experiences of discrimination by carers. Over a third of carers are still experiencing discrimination, a figure which has not improved since the 2020 survey results. Similarly, general levels of understanding of carers amongst both the community and medical professionals remain low to average. This demonstrates a need to focus further advocacy efforts on educating the community and the mental health sector about the carer role.

It is also important in this space to consider that a large number of ATSI (39%) and LGBTQIA+ (32%) identifying respondents took part in this survey. These numbers are not proportional to the reported populations of these groups identified by the ABS in the ACT.⁴ Nonetheless, the findings from the demographics of this survey highlight a need to acutely consider these groups in future policy work regarding discrimination, understanding, and inclusion of the varying identities that make up mental health carers. As mentioned in the previous survey report, further research is also required to understand how mental health carers experience and perceive discrimination in the ACT community. Further work is also required to increase understanding and address discrimination.

Safety and Wellbeing

Results from Question 14 indicate that almost half of the carers responding to the survey have felt unsafe in their role in the last 18 months. This is an experience that is shared by carers across the board, regardless of age, gender, access to supports or care recipient's mental health diagnosis. Although this has decreased since the last survey, it is nonetheless concerning that 1 in 2 carers do not feel safe in their caring role.

Whilst the question did not ask carers why they felt unsafe, one carer expressed the following in a comment:

"I am concerned that services (e.g., PACER, new model Adolescent Unit) focus on no admission or shorter stays which may be OK in some cases but is it also camouflaging the need for cost savings, reducing need for beds in which case the burden is put squarely back on the carer to provide higher level acute care to the person they care for...at considerable emotional and financial cost to the family. Is this also why a significant number of carers report not feeling safe?..."

⁴ See "Estimates of Aboriginal and Torres Strait Islander Australians," Australian Bureau of Statistics, publication August 2018 (accessed June 2022), <https://www.abs.gov.au/statistics/people/aboriginal-and-torres-strait-islander-peoples/estimates-aboriginal-and-torres-strait-islander-australians/jun-2016> ; "General Social Survey: Summary Results, Australia," Australian Bureau of Statistics, publication June 2021 (accessed June 2022), <https://www.abs.gov.au/statistics/people/people-and-communities/general-social-survey-summary-results-australia/latest-release#social-experiences>.

This comment poses a significant question; are carers feeling unsafe because they are left in unpredictable acute mental health situations? There has been significant discussion around the impact of mental health service policies moving away from institutionalisation; leaving the majority of caring responsibilities for people with mental illness to their carers.⁵ The 2021 ACT PACER (Police Ambulance Clinician Early Response) performance report noted that over 77% of people experiencing acute mental health crises remained in the community after engaging with PACER.⁶ However, despite what may be a positive outcome for the consumer and PACER, mental health carers are often left in domestic situations of aggression and violence lacking the requisite training or skills to deal with them. When balancing the tensions of feeling unsafe with the love for the care-recipient, the stigma of mental illness, and avoidance of incarceration, carers are left with little to no alternatives. The comment therefore opens a discussion for both the need for increased service provision in forms such as emergency respite options, as well as the need for further support in the form of training and resources.

Other factors that may lead to carers feeling unsafe could be socioeconomic factors such as housing, lack of services, insecurity about employment, fears relating to the COVID-19 pandemic or a lack of support for their own physical and mental health. One carer noted that they felt unsafe *“only due to the toll it takes on health.”* Evidently, findings from the 2021 Carer Wellbeing Survey (‘Wellbeing Survey’) acknowledge that this sentiment is one regularly felt amongst 48.8% of Australian carers.⁷ The Wellbeing Survey also notes that 55.5% of Australian mental health/psychosocial disability carers report having only fair or poor general health.⁸ In contrast, just 20.7% of the ‘average’ Australian population report having fair or poor general health.⁹ In the case of carers, various studies have linked these poor health indicators to increased stress and burden.¹⁰ Patterns of increasing carer burden and distress have likewise been found in several parts of this survey. Comments to the effect of *“I struggle to care for myself now...”, “the pressure and drain of caring can be immense”* and *“I’m exhausted”* substantiate a greater need for support that will provide mental health carers more time to look after their own wellbeing.

It is important to note that mental health carers have sought support increasingly when compared to the last two surveys. Whilst this can be interpreted as a good sign, it may also indicate increasing carer burden. Even with a high rate of support service access, impact on carer safety and distress continues to be an issue throughout the survey results. This suggests that carer supports are only one component in achieving greater carer wellbeing. When asked for areas of improvement, carers mentioned several issues contributing to their caring burden. This included exclusion of carers, low quality and quantity of services, and poor continuity of

⁵ See generally Eric D. Johnson, "Differences among Families Coping with Serious Mental Illness: A Qualitative Analysis," *American Journal of Orthopsychiatry* 70, no. 1 (2000): 126-134, <https://doi.org/10.1037/h0087664>; K. Harvey et al., "A Review of Instruments Developed to Measure Outcomes for Carers of People with Mental Health Problems," *Acta Psychiatrica Scandinavica* 117, no. 3 (2008): 164-176, <https://doi-org/10.1111/j.1600-0447.2007.01148.x>

⁶ ACT Ambulance Service, ACT Policing, and Canberra Health Services, "PACER Performance Report" (Canberra: unpublished, 2021), 8.

⁷ Carers Australia, *Caring for Others and Yourself: The 2021 Carer Wellbeing Survey* (Canberra: Centre for Change Governance and NATSEM, 2021), 53, [211011 Carer-Wellbeing-Survey Final.pdf \(carersaustralia.com.au\)](https://carersaustralia.com.au/211011-Carer-Wellbeing-Survey-Final.pdf).

⁸ Ibid, 29.

⁹ Ibid, 26.

¹⁰ See e.g., Yun-Hee Jeon et al., "'Give Me a Break'- Respite Care for Older Carers of Mentally Ill Persons," *Scandinavian Journal of Caring Sciences* 20, no. 4 (2006), 428, <https://doi-org/10.1111/j.1471-6712.2006.00423.x>.

care. A focus on these systemic issues is likely to produce more promising results for carer safety and wellbeing. Further, it would be beneficial to have additional ACT specific research to understand the safety concerns of mental health carers and the proportion of mental health carers that experience violence or abuse.

Access and Inclusion

The survey results have indicated that access and inclusion in the mental health system continues to be a major concern for carers. In the areas of improvement, carer inclusion/support in mental health services was identified to be the most common area of concern (Table 4). Extrapolating from the survey, the questions can be divided into the following categories: Access to Mental and Non-Mental Health Services, Barriers to Accessing Mental Health Services and Carers feelings of Inclusion, Respect and Communication in the Mental Health System.

Access to Mental and Non-Mental Services

The data from Question 15 and 16 illustrated that GPs, Psychiatrists and Psychologists were the most accessed (Table 2) and most helpful services for carers. This data highlights that there are more carers accessing GPs in comparison with other mental health services. Additionally, it was showcased that private Psychiatrists and Psychologists were accessed more than their public counterparts. This preference could be due to the fact that there is a severe shortage of trained medical professionals in the ACT Public Health system. Additionally, carers have highlighted that they prefer engaging private clinicians as these clinicians have the time to communicate effectively with both the carer and care recipient and build ongoing relationships. The following comments were made to this effect:

“Private psychologist. Has the time to talk to me as the parent/carer and not just my daughter. Public system although all that I'm in a position to afford, I feel is rushed in and out and difficult to really find the time to brief the counsellor and/or psych with what's going on for my child at length, from my perspective, and raising/discussing issues with the time needed. Would be good if they allocated 10/15 mins a week, maybe after child's appointment, to discuss parents concerns.”

“Private psychologist because of their ongoing relationship with the person I care for”

However, this presents a limitation to accessibility as some carers are unable to afford a private clinician. Interestingly, the results also indicate that there was a high number of interactions with the Community Mental Health Centre (Table 2). When carers were asked which mental health service was the most useful as a carer, several stated the Community Mental Health Centre. One of the carers said that *“...they are very professional, inclusive, collaborative, compassionate, caring, and skilled especially the clinical case manager.. They are the best we have had in our 15 years experience in MH system in ACT.”* For carers who are unable to afford private clinicians, this service may be a promising alternative to consider in the future.

Conversely, Question 17 asked the respondents as to which mental health services they found to be least helpful in their capacity as a carer. The results showed that Psychiatrists, Psychologist, School Psychologists and GPs were among the most mentioned. These poor experiences were marked by limited communication with carers, a lack of understanding of the complexities of mental health, and long waiting times. The results from Question 15 to 17 indicate an overlap between GPs, Psychologist and Psychiatrists as most accessed, most

useful, and least useful. This highlights the need for a holistic approach to educating clinicians on carer communication and engagement.

Questions 19 to 21 asked the respondents to provide their feedback in relation to non-mental health services. Specifically, the most accessed, most and least useful respectively. The most accessed non-mental health service was Centrelink, Housing, Education, Legal and NDIS services. Of those services most carers said that none of them were useful. This is primarily due to overcomplication and delay in service. Of the response it can be deduced that there is an acknowledgement that services were being provided, but of poor quality.

Barriers to Access

Significant barriers to access have also been highlighted in the survey responses. Question 18 indicated that 34% of the respondents had to travel interstate to access mental health services. Despite COVID-19 restrictions in 2020 and 2021, this number has increased slightly from the 2020 survey. This means that accessibility is limited such that carers are required to travel through a pandemic to access necessary services. One of the respondents noted that both financial accessibility and capacity is limited within services in the ACT, requiring them to travel interstate.

Carer feelings of inclusion, respect, and communication

Results from Questions 23 and 24 provided us with an insight into Carers feelings of inclusion, respect, and communication. Question 23 specifically indicated that respondents have only experienced inclusion, respect, and communication with mental health services occasionally or approximately half the time in the last 2 years. This has slightly improved when compared to the results from last year. This may be due to the influence of the *Carers Recognition Bill* (now *Carer Recognition Act 2021* (ACT)) and relevant advocacy work. However, given the low medians there is still considerable work to be done in all areas; particularly carer contact on admission, having carer wellbeing been factored into treatment plans, and carer's having choice and control over the care they provide (Table 3).

Most concerning of this data were the results of Question 22 which indicated that 23% of carers were excluded from the mental health services, despite the consent of their care recipient. This showcases a decline in communication between treatment teams and carers in relation to the process of obtaining consent from care recipients or the attitude of treatment teams towards following the care recipients wishes. It would be beneficial to engage in further research to fully understand these issues.

As mentioned in the results, the IQR for the data under Question 23 is low enough in both years to indicate that a majority of carers have not been having vastly different experiences of the mental health sector (Table 3). In comparison to the 2020 survey results, the opinions of the respondents were more polarised as opposed to varied. This may suggest that slow systemic change has positively influenced the mental health system and carer experience.

Carers perceptions of inclusion, respect and communication for other carers was assessed in Question 24. The results showed that there was a growing perception that the system is getting worse (Figure 9A). Despite a statistical improvement in the data for Question 23, it appears that carers still do not visibly see or feel an improvement in the mental system for carers. Strikingly, further results from Question 24 show that more carers who are not sure about past experiences perceive that inclusion, respect and communication is happening regularly in the ACT. This could be because limited knowledge of past experiences or limited time in the mental

health system favours a more optimistic outlook towards the inclusion, respect, and communication of services in the ACT.

Limitations

There were a number of limitations that should be acknowledged when interpreting the results from this survey. These limitations are sample size and ambiguity in survey construction.

Despite the larger sample size in comparison to the previous surveys, the total of 113 responses do not represent the total number of mental health carers in the ACT.¹¹ There may also be an overrepresentation of certain identity groups compared to the overall population of the ACT given the channels this survey was marketed through. As such, there is risk in extrapolating trends and significant difficulty when comparing to the much smaller sample sizes of the previous two surveys. Given the increased response of this survey, future surveys would also benefit from paid advertising or incentivising responses.

Demographics could be examined further. This survey did not ask about the age of care recipients, or the nature of carers relationships to them (i.e., parent, friend, partner). This should be considered for inclusion in future surveys, particularly those examining the safety of carers. The survey also did not effectively ask about the experiences of people caring for multiple care recipients. Furthermore, the construction of Question 24 presented difficulties in interpretation.

CONCLUSION

Overall, this survey provided a valuable opportunity to reflect on the changes in mental health carers experiences of the mental health system in the ACT over the years. The results obtained from this survey gave us insight into the mental health carer's experiences with discrimination and understanding, safety and wellbeing, and access and inclusion. While the results demonstrate slight improvement in certain areas, it is evident that further research, advocacy, and policy work is required to ensure that carers are provided a robust and inclusive mental health system in the years to come.

¹¹ "Disability, Ageing and Carers, Australia: Summary of Findings," Australian Bureau of Statistics, publication October 2019 (accessed May 2022), [Disability, Ageing and Carers, Australia: Summary of Findings, 2018 | Australian Bureau of Statistics \(abs.gov.au\)](https://www.abs.gov.au/ausstats/abs@.nsf/0/44010155000000000000000000000000?openview).

REFERENCES

- ACT Ambulance Service, ACT Policing, and Canberra Health Services, "PACER Performance Report." Canberra: Unpublished, 2021.
- Australian Bureau of Statistics. "Disability, Ageing and Carers, Australia: Summary of Findings." Published October 2019. Accessed May 2022. [Disability, Ageing and Carers, Australia: Summary of Findings, 2018 | Australian Bureau of Statistics \(abs.gov.au\)](#).
- Australian Bureau of Statistics. "Estimates of Aboriginal and Torres Strait Islander Australians." Published August 2018. Accessed June 2022), <https://www.abs.gov.au/statistics/people/aboriginal-and-torres-strait-islander-peoples/estimates-aboriginal-and-torres-strait-islander-australians/jun-2016>.
- Australian Bureau of Statistics. "General Social Survey: Summary Results, Australia." Published June 2021. Accessed June 2022. <https://www.abs.gov.au/statistics/people/people-and-communities/general-social-survey-summary-results-australia/latest-release#social-experiences>.
- Carers Australia, *Caring for Others and Yourself: The 2021 Carer Wellbeing Survey*. Canberra: Centre for Change Governance and NATSEM, 2021. [211011_Carer-Wellbeing-Survey_Final.pdf \(carersaustralia.com.au\)](#).
- Harvey, K., J. Catty, A. Langman, H. Winfield, S. Clement, E. Burns, S. White, and T. Burns. "A Review of Instruments Developed to Measure Outcomes for Carers of People with Mental Health Problems." *Acta Psychiatrica Scandinavica* 117, no. 3 (2008): 164-176. <https://doi-org/10.1111/j.1600-0447.2007.01148.x>.
- Jeon, Yun-Hee, Henry Brodaty, Colleen O'Neill, and Jon Chesterson. "'Give Me a Break'- Respite Care for Older Carers of Mentally Ill Persons." *Scandinavian Journal of Caring Sciences* 20, no. 4 (2006): 417-426. <https://doi-org/10.1111/j.1471-6712.2006.00423.x>.
- Johnson, Eric D. "Differences among Families Coping with Serious Mental Illness: A Qualitative Analysis." *American Journal of Orthopsychiatry* 70, no. 1 (2000): 126-134. <https://doi.org/10.1037/h0087664>.
- Kostoulas, Achilles. "How to interpret ordinal data." *Applied Linguistics & Language Teacher Education* (blog). February 23, 2014. <https://achilleaskostoulas.com/2014/02/23/how-to-interpret-ordinal-data/>.
- Kostoulas, Achilles. "On Likert scales, ordinal data and mean values." *Applied Linguistics & Language Teacher Education* (blog). February 13, 2013. <https://achilleaskostoulas.com/2013/02/13/on-likert-scales-ordinal-data-and-mean-values/>



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