

ACT Budget Response 2019/20

Carers ACT

Peak Body in the ACT for Mental Health Carers

19 June 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 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 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 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.

Carers ACT is the Peak Body in the ACT for Mental Health Carers

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1. Introduction:

Carers ACT has welcomed the release of the 2019-20 Budget by the ACT Chief Minister and Treasurer Andrew Barr MLA. It has demonstrated the government is prioritising Mental Health in the Canberra region and is a positive step forward for improving services for our mental health carers and the people they care for.

We have been advocating across many platforms on the issues carers have identified to us as important for them, in particular, for greater carer inclusion, respect and support in their roles.

As the peak body for mental health carers in the ACT we have we been proud to work with many carers over the last year through consultations, in meetings with decision makers, in committee work, in undertaking research and in designing systems and advocating for change. We are a rights-based, evidence-informed policy and advocacy peak organisation representing the needs of mental health carers in the ACT.

The following paper addresses the priority issues for mental health carers and the how the budget initiatives are working to meet those needs.

2. Priorities issues for mental health carers

In developing our advocacy platform, we regularly consult with our mental health carer membership. We have an e-bulletin that is distributed monthly to our 747 subscribers, we run surveys, host forums and focus groups and run consultations on key issues. We also participate in committees with ACT Health, ACT Office for Mental Health and Wellbeing, Capital Health Network, Peaks and NGOs, ANU and more.

In 2018 we undertook The **Mental Health Carers Voice Priority Needs Survey** which identified the following key issues;

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

a. Carers need to be included, respected and supported in their role

Mental Health carers provide a valuable, kind and selfless duty in our community that is made more difficult because many services exclude them, disrespect them or do not support them and what they do.

When carers are not included this can be detrimental to carers health and wellbeing. Mental health carers are an at-risk group and have high rates of mental illness themselves along with poorer physical health. They are also more likely to delay seeking medical help for themselves when they are unwell. Carers can often be kept away from treatment decision making conversations and yet there remains an expectation that they will be available to care and be able to cope without information about the illness or the treatment at home.

Greater carer inclusion, respect and support is an identified priority need for mental health carers and, as many carers know, if addressed, it has flow on effects that benefit the people they care for, the health services they use and the wider community.

In research conducted in 2016 they found that within the mental health services, Family Psychoeducation was part of ideal treatment for improving outcomes for both patients and carers. This was also demonstrated in a larger review undertaken 2015, where evidence was supportive of the impact support groups had for carer wellbeing.

There is strong demand from Canberra carers in our 2018 Carer Priority Needs Survey for greater carer support services for mental health carers and the comments were demonstrative that carers continue to struggle to get the information they need to be able provide care and be included in treatment discussions and decision making. This can include the need for improved respectful two-way communication where carers can communicate to a mental health professional all the symptoms they are seeing and have someone respond with empathy and appropriately to the severity.

Many studies have demonstrated the reduced need for hospitalisation of those with severe acute mental illness if carers can be provided with adequate information about managing mental illness, discharge support and receive in-home intensive support if acute, especially for young people. However, for carers, there is currently no consistently good options for managing acute mental illness at home and so they are forced into the hospital system.

b. Improved awareness and decreased stigma in non-mental health services about mental health and caring

Mental health carers continue to experience barriers to service accessibility and decreased social acceptance because of misunderstanding and stigma associated with mental illnesses and caring for someone who has a mental illness.

Severe mental illness continues to be difficult for many people to understand and understanding what caring for someone with a mental illness entails is even more difficult. As a peak body, our membership is more anonymous than many would be aware.

Most mental health carers either do not feel comfortable identifying with the word 'carer' or do not have permission from the person they care for to discuss their caring role widely because of the stigma of mental illness. Canberra is a small city and it is likely to work with or know someone socially through multiple channels so many carers do not want to advocate in our public forums or via the media. This perpetuates the lack of awareness and stigma but is also difficult to break.

In research conducted by ANU Centre for Mental Health Research Unit ACACIA they asked, "*Whose story is it?*" examining the ethics surrounding research participation, in particular looking at a carers ability to participate in research without the consumers consent. And it is an ongoing issue in mental health service delivery— but we also see it in the word 'carer'. Some carers feel that if they identify that they are a carer it implies labelling an imbalance in the relationship and that it is defining a burden. Once someone identifies themselves as a 'carer', they have identified that the other person is making their life hard.

This then feels like blame and so the word ‘carer’ is heavily loaded. This is especially true for mental health carers who do not have a clear moment of diagnosis where duties begin and caring will often start with offering emotional support, which is normal in any relationship, so when does this become ‘more than normal’. This dynamic can be further complicated by relationship factors and age-related factors etc.

In the 2018 Carer Priorities study carers identified that there was across Canberra a poor understanding of mental illness and carers, in particular services such as GPs, Centrelink, housing, and schools were mentioned. In the comments section carers mentioned that in talking in their workplaces or to their families and friends, Canberra also still needed more carer awareness.

c. Prioritising wellbeing through early intervention and improved care coordination to create mentally healthy communities

Carers and the mental health community are in unison on the importance of prioritising early intervention. This third identified carer need was about reducing the prevalence and/or severity of mental illness through improved accessibility of early intervention services and care coordination.

Many of the issues that carers identified were related to the difficulties associated with very complex service navigation for people who already have diminished capacity and that people had to reach a threshold level of unwell before they could access services. Consistently carers tell us that they get knocked back from services because the person they care for was not ‘unwell enough’.

Early intervention we can think of both through the lens of time from first symptom onset to accessing diagnosis and treatment and, following this, each episode of acute symptoms and how quickly the person can access mental health services that meet their needs and the needs of the carer. Early intervention is therefore often focused on improving peoples understanding of mental illness symptoms, knowing how to access services and decreasing waiting times for services.

Coordinating the many services involved in a person with severe mental illness’s life is one of the most complex components of the system and care coordination is well documented for its effectiveness not only in improving mental health treatment compliance but also managing concurrent physical health conditions in mental health consumers. Improving service integration is one component of this discussion, integrating community mental health services, disability services, primary health care services, carer support services and the ACT Mental health service is an enormous task.

d. Increased quantity and quality of Mental Health Services

As Canberra’s population increases there is not only an increasing demand for services but there is an increasing need to diversify our service composition to meet needs and improve quality of services. Consistently research is demonstrating that within mental health, tailoring a therapeutic method to suit the client and their illness alongside their medication regime is best practice, however most clinicians are not specialists in all therapeutic methods and usually specialise in one. In practice, most clinicians practice cognitive behavioural therapy. However more and more we are seeing other therapeutic methods becoming more available.

There is also a need for increased quantity of services to decrease the wait time and to ensure the right service is delivered at the right time. Quantity and quality go hand in hand and there is a need to ensure that we have both the staffing levels to facilitate the population size, but also the right skills mix to ensure that all patients receive the best form of care.

Carers consistently tell us the difficulty of finding good clinicians in Canberra, of long wait lists, of finding a good GP who understood mental health and the importance of finding someone who will be the right fit for the person you care for.

3. Budget initiatives for mental health carers

a. Strengthening capacity for mental health carers

We were very pleased to have it confirmed in the budget funding specifically for two Carer Engagement Clinicians to work with mental health carers to pilot a range of different support programs and psychosocial education activities. This was a something we had been actively involved in advocating for since it came through so strongly in the survey results and, we've been pushing it through a number of key committees that we sit on.

This is a direct example of the initiatives that can result from clear campaigning from mental health carers and we are very excited for the next phase of work to begin. We have already confirmed that we will continue to be working with ACT Health to recruit for the two positions and design the work that they will be undertaking and ensure that they have an ongoing dialogue with this program going forward.

What this means now:

In the coming months we will advertise in the e-bulletin a focus group, survey or a consultation where we ask for some input into what you needed when the person you cared for was in hospital? What you think a carer engagement clinician should do? Or contact the Mental Health Carers Voice program at any time via mhcarers@carersact.org.au .

b. Adolescent Inpatient Mental Health Unit

Within the expansion of the Centenary Hospital for Women and Children there is the inclusion of a mental health ward for young people for mental illness. It is going to be a 6-8 bed unit and we are pleased to confirm that it comes with an associated day program and an intensive in-home family support program. We were heavily involved in the consultation for this project and we see it as positive example of whole of person and family care. We are pleased to see the investment and we will continue to be involved to ensure that the associated services and their importance to achieving positive outcomes for the consumer and the carer are maintained.

The investment here is clear, they are investing in more mental health services, which is a good thing as long as it is a good quality mental health service. Our involvement so far has been to ensure that balance of quality and the investment we have advocated for alongside the infrastructure are what carers should be most proud of. The intensive in-home family support service advocated for will allow families to feel safe about going home knowing they've got supports in place. And the day

program is also very important so that treatment isn't over medicalised and the therapeutic arm is maintained, which was made possible through the strong carer representation involved in this committee.

In fact, this could meet all the identified areas, as an adolescent inpatient mental health unit that would also meet the priority need of early intervention for these young people, because it is early in their journey of mental illness. With the Model of Care in development and the in-home family support service we have an enormous opportunity to put carer inclusion, respect and support into the framework for the project and advocating that the services integrate well with the rest of health should be on the agenda, in particular that as people transition we have good communication that will be key for this project. The opportunity is here to embed the identified priorities carers have articulated above into this from the beginning.

What this means now:

The expansion is larger than the Adolescent Inpatient MH Unit - over the next 4 years they are investing \$42.49b in the Centenary Hospital alone. We are not sure when they will be undertaking the adolescent MH unit part of the infrastructure works - as they will need to shut down different parts of the hospital in different stages. There's lots of planning that is needed to make decisions, so we'll let you know when we have more information. We will keep you informed through the e-bulletin and Carers ACT will have continued involvement in the Adolescent MH Unit Working Group recommencing in June 2019.

c. Expanding public inpatient mental health care

The largest investment in mental health is going to increasing the permanent staffing at the Adult Mental Health Unit (AMHU), theoretically lifting the number of beds from 37 to 40 beds. However, in practice the AMHU has consistently operated at a 40-bed capacity with fewer staff than recommended so this would simply be reflecting the appropriate operating staffing to be effective at the current capacity. To see the funding allocated for the increased staffing in the budget was a welcome relief - it will be likely result in easing strain on the workforce and improve the quality of care that is able to be provided. It responds to the sector need for increased quantity and quality of mental health services broadly.

What this means now:

This means that there will be 40 beds available at the AMHU and that they will be hiring some new staff to look after patients on the ward so that the staff to patient ratio is slightly higher. Crucially, in progressing this our advocacy on this forward, staffing provides us with an opportunity to examine the workforce strategy and see how the elements of improved quality of care in mental health services can also be improved alongside the increased quantity.

d. Delivering better mental health care for people in crisis

The Government announced the planning and delivery of the PACER model in the budget. The Police, Ambulance, Clinician, Early Response (PACER) model provides better support for those experiencing an acute mental health incident by helping to coordinate those different services to

deliver a unified assessment and avoid unnecessary hospitalisations. We are very keen to see PACER in the budget announcement as we have heard of the model in other contexts and know that it has done well overseas. We have also had quite positive feedback from our mental health carers who have had experiences with the police services. Whilst not an early intervention strategy, it is an excellent example of investing in better service integration, so working towards that care coordination that we have been advocating for and it also focused on reducing unnecessary hospitalisations, which is also a positive initiative as long as we put pressure on carers to be heavily involved in decision making and supported within the model.

What this means now:

The funding is to plan and deliver the PACER model in the 2019/20, we've already had contact for some preliminary conversations and we'll be advertising for a consultation shortly.

Our preliminary thoughts on this issue is that we need to ensure the PACER model has the carer inclusion, respect and support principles at its core and works very closely with families when making decisions regarding whether to stay at home or to go into hospital.

If you would like to know more about the PACER model and how it went in Victoria please send us an email.

e. Expanding Public Health Care services for Eating Disorders

Government announced funding in the Budget for a specialist clinical hub for the treatment of eating disorders and a community-based intervention support services. In the 2019-20 year it will only be planning/design work preliminary funding however, it appears as if they intend to deliver some services in 2020-21.

Eating disorders are incredibly complex to treat and care for and both our physical health system and our mental health systems have struggled to treat both needs and work towards recovery from acute levels. Whilst there are many complex conditions that the Government could have tackled this budget, eating disorders are definitely an important issue in our community and we applaud their willingness to engage with complex issues.

What this means:

At this point it is unclear where the service would be located and who would be funded to be delivered it. We will let you know when we find out and we will be actively involved in the development of the hub and the services.

We would like to know if you are a carer registered with us who has experience caring for someone with an eating disorder because your experience could help us to understand what needs to change and if you went somewhere that was really good – that's really good to know as well.

f. Funding for Mental Health in public schools

Carers ACT were very pleased to see the commitment of the Government investing in permanently funding four full time school psychologists and one administrative support worker to promote student wellbeing and better mental health among young Canberrans. The budget was largely focused on health initiatives, so this was a win for investing in early intervention in mental health. The importance of having trained mental health professionals in schools to be able to do assessments and also to promote awareness of symptoms of mental illness, how to talk to friends, when to seek help and provide evidence based strategies that are early intervention is imperative to building resilience, life skills and recovery in young people.

What this means now

It is unclear whether the staff will be at high schools or primary schools or whether there are certain high priority schools that have been identified, but we would be interested in hearing more about the initiative. We are curious as to why psychologists were specified rather than social workers/counsellors, or rather than keeping it broad. We will be advocating for these professionals to integrate families/carers into their work.

4. Summary

Overall the budget sold itself as investing in a growing population however it largely was investing in meeting the needs that had previously been identified by the sector. The large investment in health is welcome but expected. What is very exciting about this budget is that there appears to be a real turn toward hearing the needs and adapting practice within mental health services, especially with the carer engagement workers. As we know from previous years, the budget announcement is merely the first step and we will continue to advocate for the design and implementation of these initiatives to focus on the carer needs articulated above.

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