Carers ACT Comments for the Standing Committee on Health, Ageing, Community and Social Services' *inquiry into Youth Suicide and Self-Harm in the ACT.*

April 2016

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.

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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 43,000 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 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 a member of the National Network of Carers Associations, and works actively with other States and Territories to share knowledge and facilitate improved health and wellbeing outcomes for caring families.

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Committee Secretary

Standing Committee on Health, Ageing, Community and Social Services

GPO Box 1020

Legislative Assembly for the ACT,

CANBERRA ACT 2601

Submitted via email: committees@parliament.act.com.au

Youth Suicide and Self-Harm in the ACT

Carer ACT welcomes this opportunity to provide comments to inform the Standing Committee on Health, Ageing, Community and Social Services' inquiry into Youth Suicide and Self Harm in the ACT.

As the peak body for mental health carers in the ACT, we regularly support and advocate for carers of people experiencing mental illness and mental disorders. Youth suicide and self-harm is of serious concern for many carers, especially as the rates of suicides for young people appear to be increasing and it continues to be the leading cause of death among Australians aged between 15-24 years.

In addressing issues relating to suicide and self-harm it is crucial to incorporate carers' voices into the inquiry and to understand the multifaceted carer experience with self-harm and suicide. This submission draws on feedback from mental health carers and Carers ACT's Counselling and Young Carers program teams and shall focus on the following four key areas;

1. Defining and classifying suicide
2. Accessibility of evidence-based self-harm reduction programs
3. Young carers at risk of self-harm and suicide
4. Unique factors for youth suicide risk in the ACT

Defining and classifying suicide

Carers ACT make recommendations that the inquiry should acknowledge the limitations on suicide and self-harm statistics and endeavour to establish more comprehensive metrics. This would begin to define the scope of the issue within the ACT, in order to have an appropriate service response.

There is an ongoing debate regarding classifying a death as a suicide in the ACT. As the coroner needs to determine 'the burden of proof' to establish that a death was suicide and not an accident or assault, making a finding of suicide as cause of death can be difficult.

For a death to be classified as a suicide in Australia, it must be;

"…established by coronial enquiry that the death resulted from a deliberate act of the deceased with the intention of ending his or her own life (intentional self-harm)."[1]

[1] ABS, Causes of death, 2009, op. cit., p. 25.

The classification of "*intentional self-harm"* as cause of death can apply to a number of other circumstance in which the individual had no suicidal intent including self-harm behaviours as coping mechanisms. It is therefore broader than a suicide statistic to examine the statistics on intentional self-harm. Also, if it cannot be determined whether the deceased was intentionally ending their own life it will be classified as *undetermined intent*.

There is, therefore, a concern that the current data we have in the ACT is merely the 'tip of the iceberg' and the true extent of the problem is far greater. In order to improve the quality of cause of death data, the ABS has expanded the length of time for review of the coroner certified deaths before publication; however there are still many cases of undetermined intent that could inflate the numbers considerably (see Table 1).

Table 1: Selected external causes of death in Australia, mechanism by intent, 2009

	Accidental death	Intentional Self-Harm	Undetermined intent	Total
Poisoning	779	566	345	1690
Hanging	220	1093	127	1440
Drowning and Submersion	182	43	54	279
Firearms	6	164	24	194
Contact with sharp objects	9	55	22	86
Falls	1370	81	29	1480
Other (a)	2736	130	393	3259
Total	5322	2132	994	8448

(a) Includes sequelae, explosives, smoke/fire/flames, blunt object, jumping or lying before moving object, crashing of motor vehicle (solo).
Source: ABS, *Causes of Death 2009*, cat. no. 3303.0,ABS,Canberra, 2011, p. 29.[2]

Carers who lose the person they care for to suicide experience the confronting and confusing process of a coronial investigation to examine the circumstances of the death. Coming to terms with a family member committing suicide is a grieving already complicated with stigma and guilt[3] and to have this blurred or invalidated can increase difficulty in processing the grief and trauma[4].

The prevalence of self-harm is also not clear. As self-harm does not always lead to medical treatment, there are potentially many cases that are not picked up in standard data collection devices. In 2010[5] a community survey on self-injury was undertaken with 12, 006 Australians from randomly selected households. This study found that 4% of females aged 15-19 years had self-

[2] Simon-Davies, J., 2011, *Suicide in Australia*, Parliament of Australia, Statistics and Mapping Section, Canberra [accessed on 7/04/2016; http://parlinfo.aph.gov.au/parlInfo/download/library/prspub/959600/upload_binary/959600.pdf;fileType=application/pdf#search=%22background%20note%20(parliamentary%20library,%20australia)%22].

[3] Young, I.T., Iglewicz, A., Glorioso, D., Lanouette, N., Seay, K., Ilapakurti, M. and Zisook, S., 2012. *Suicide bereavement and complicated grief*. Dialogues Clinical Neuroscience, 14(2), pp.177-186.

[4] Dunn, R.G., & Morrish-Vidners, D., 1987. *The psychological and social experience of suicide survivors*. Omega, 18, 175-215

[5] Martin, G., Swannell, S.V., Hazell, P.L., Harrison, J.E. & Taylor, A.W., 2010. *Self-Injury in Australia: a community survey.* MJA **193**: 9, pp. 506-510

harmed in the 4-weeks prior to the interview. For males the rate of self-injury was 2.3% for those aged 10-14 years and 2.2% 15-19. Only 14.3% of those who had self-injured in the 4 weeks prior to the interview had sought and received medical treatment.

For carers this is important because of how their caring role is supported by the treatment and care services available to the person they care for as well as the carer support services available to them. If the person they care for is not engaging in service that does not mean that the carer does not provide care and can often mean that the demands on the carer are greater. This can have serious consequences, not only to the person who is self-harming or suicidal but also negatively impacts on a carer's health and wellbeing, including negative impacts on their mental health. Therefore, having access to accurate prevalence of self-harm and suicide shall enable us to;

1) Infer how many people in the community are and are not accessing treatment or support;

2) Determine what services are needed; and

3) To support carers in their roles; through increasing the ability for the people they care for to access services, by providing carer support services to ease other aspects of their life and enable them to devote the time necessary for their caring etc.

Suicide prevalence should also, preferably not be measured by completed suicides alone. In order to engage a robust discussion on youth suicide, it is important to look at the full array of suicidal behaviours including suicidal ideation and suicide attempts. Through increasing our understanding on these areas it may provide further insight into what interventions are most effective for young people and consequently ease the carer's role.

Accessibility of evidence-based self-harm and suicide intervention programs/treatment

"I know there are some good services around, but the wait times are so long, we did it a while ago but by the time we got in they said he wasn't sick enough anymore. All this [mental health] it fluctuates and it's so hard to find someone to see them [the person I care for], it's not like you can pick the kind of therapy that you need, they just have to go with whoever is available. It makes it really difficult, I try to support him to get treatment but it feels like lots of closed doors." [ACT Carer, 2016].

In addition to the fears and anxiety that carers of this population experience, they are also faced with a difficult challenge. Firstly, in trying to support the person they care for to access formal treatment and secondly, getting access to the right type of treatment when it is needed.

Young people tend not to seek professional help and young people are even less likely to seek help if they are experiencing suicidal thoughts and depressive symptoms. In a Queensland study of 3092 young adults, aged 15–24 years, 39% of the males and 22% of the females reported that they would not seek help from formal services for personal, emotional or distressing problems[6]. In a review on perceived barriers for adolescents and young adults accessing mental health treatment, they found

[6] Rickwood, D. J., Deane, F. P., & Wilson, C. J. (2007). When and how do young people seek professional help for mental health problems?. *Medical Journal of Australia*, *187*(7), S35.

that help-seeking was severely less if a person had a previous negative experience try to access services[7]. This could include;

- Long waiting times to access the service
- Inappropriate service for need; especially in the treatment of self-harm, the mental health literacy to understand the distinction between self-harm and suicide is crucial.
- The quality of the therapeutic relationship
- The expense of the service and the ease of attending appointments; especially for young people who may not wish to have family aware of their treatment ie. that the services be located close to public transport and extending the ability for phone counselling and online CBT programs[8].

Best-practice treatment options for self-harm and suicidal behaviours currently is considered targeted CBT programs aimed at reducing self-harm or suicidal behaviours paired with treatment for any associated mental health problem (ie. treatment for depression, anxiety, personality disorders etc.)[9]. It is crucial that there is the capacity for therapy to examine the reasons behind the self-harm and suicidal behaviours, especially considering the strong association between experience of trauma and self-harm/suicide. At Carers ACT, our carers have expressed the difficulty in getting all these elements in place when they are needed;

"You finally get them [the person I care for] to agree to see someone, and it's can be months waiting to get into the psychologist who works with self-harm and you don't want to go to just anyone because you don't want them to have a bad experience, it's hard enough to get them there in the first place and then if it didn't work, if they didn't know how to work with her, I don't think she'd do it again" [ACT Carer, 2016].

One of the largest stressors on mental health carers in the ACT is assisting the person they care for to find a service. However, the onus is on the young person to have the motivation to find a service, book an appointment and organise transport and then after the appointment, follow up with any referrals and coordinate their care plans. Whilst carers often take on the bulk of these roles, a more assertive outreach treatment would be beneficial when working with this population, to allow carers to focus on their familial role, rather than a case coordination role.

In summary, Carers ACT recommends that the inquiry should look into;

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[7] Gulliver, A., Griffiths, K. M., & Christensen, H. (2010). Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review. *BMC psychiatry*, *10*(1), 113.

[8] The ACT snapshot in the 2015 Mission Australian' Young People Survey identified that the ACT young people ranking on satisfaction or happiness with their life was close to the national average (63.4%), but more ACT young people % were less happy, with ACT having a higher 'very sad rate' 7.5% than the national rate at 1.7%. ACT young people 14% were 'extremely concerned' or very concerned about suicide, 15.9% were 'somewhat concerned' or 'slightly concerned' about suicide. For more details see https://www.google.com.au/?gfe_rd=cr&ei=2kMKV4LTKqLM8gepxaqwDg&gws_rd=ssl#q=mission+australia+young+people+survey

[9] Hawton, K., Arensman, E., Townsend, E., Bremner, S., Feldman, E., Goldney, R., ... & Owens, D. (1998). Deliberate self harm: systematic review of efficacy of psychosocial and pharmacological treatments in preventing repetition. *Bmj*, *317*(7156), 441-447.

- Improving the capacity of evidence-based, best practice interventions in the ACT to decrease waiting times and make response timelier.
- Comprehensive mental health literacy training for medical professionals including general practitioners, specifically looking into understanding self-harming and suicidal behaviours and planning comprehensive treatment plans.
- Increasing the availability for high quality online therapies such as CBT at no cost for young people as an early intervention strategy.
- Provide more assertive case management of care plans; understanding that this is a group that has difficulty engaging with mental health services for a number of reasons.

Young carers at risk of suicide and self-harm

Young carers are children and young people aged up to and including 25 years. Characteristics of young carers are:

> … young people living in a household with a child or adult with a disability, long-term health condition or impairment, which is ongoing and restricts everyday activities, and hence, may be involved in the care or support of that person or may have more intangible responsibilities … These young people may not have identified as a carer for two reasons: first, they may not have self-identified as carers themselves; or second, they may provide support and assistance for activities other than the core activities of self-care, communication and mobility.[10]

Various research projects about young carers continue to identify the significant impact of young carers providing care without support, including risk factors for mental health issues, and the need for government policies and programs to reduce these risks through identification, early intervention and responsive services to address this. The impact of caring means young carers

- Are more likely to live in households with low incomes that experience financial disadvantage
- Are less likely to complete secondary school or begin tertiary level than non-young carers because of their caring role. Research suggests only 4 per cent of young carers aged 15 to 25 years are still in education, compared to 23 per cent of non-young carers
- And their family are at risk of child protection services intervention if insufficient family-centred supports exist
- Often experience lower participation in friendship networks, social, sporting and other recreational activities, with resultant lower levels of social connectedness and personal health and wellbeing than non carer peers
- Can also experience stigma because of their caring role, or living in a household with a parent or sibling who has a disability or mental illness.[11]

[10] Australian Government Department of Social Services (updated April 2014) *Young carers in Australia: understanding the advantages and disadvantages of their care givin*g, SPRC Research Paper 38. Accessible at http://www.dss.gov.au/about-the-department/publications-articles/research-publications/social-policy-research-paper-series/number-38-young-carers-in-australiaunderstanding-the-advantages-and-disadvantages-of-their-care-giving?HTML#analysis

[11] Information on young carers is available at www.carersaustralia.com.au

Carers ACT supports 288 young carers in the ACT through its Young Carer Program and its Mental Health Respite Program for Young Carers. We currently have 106 young carers caring for someone with a mental illness. Our data indicates:

- 62% care for a parent
- 31% care for a sibling
- 5% care for both parent and sibling
- 70% live in a family with at least one sibling with a caring role.

They are more likely to care for a single parent mother, usually because alternate informal care from other adults in their families is unavailable.

Carers ACT conducted two young carer focus groups in 2014 with participants aged 7-11 years and 12-16 years that identified some young carers were either experiencing their own mental health issue, or had been exposed to or were impacted by the following mental health risk factors.

- Domestic and family violence
- Drug and alcohol dependency (parents and sometimes young carers)
- Bullying at school
- Self-harm
- Suicide attempts of parents
- Loss and grief
- Difficult family relationships
- Child abuse (including sexual abuse) and no or limited access to victim support
- Lack of trust ignorance, lack of empathy and stigma or stereotype
- Inadequate support at school and socially.[12]

Carers ACT has continued to strongly advocate for the need for increased awareness about young carers by schools, health providers and family support services to mitigate their risk of mental health issues that can continue post education. Children and young people often feel unable to speak with peers, teachers and service providers about being a carer because of negative perceptions about their carer role, and the illness or disability of their family member.

The Youth Coalition of the ACT (YCA) through its consultations on perceptions of mental health of young people in the ACT found that young people specifically identified teachers as a key group that could play an important role in supporting their mental health. It recommended that:

- School staff require ongoing professional development to identify, understand and refer issues that may arise – including provision of information about local services that are available for referrals
- Teachers need to be trained so they have appropriate knowledge and skills to understand bullying and mental health issues
- Schools and teachers require extra support to deal with crisis situations in the classroom and in the playground
- Schools need to have embedded mental health supports including health professionals, youth workers, social workers, and psychologists must be embedded within schools to deliver integrated, efficient and effective mental health support to students.

[12] Carers ACT (2014), unpublished data.

Among students at risk of mental health issues and a higher risk of education disengagement YCA included students who were young carers.[13]

Through its Young Carer Program, Carers ACT has successfully developed relationships with some schools and colleges in the ACT to raise awareness about young carers and its impact, and has also provided case management and referrals for young carers and their families to appropriate services – including family intervention services, young carer counselling, and respite to provide necessary support for young carers to have a break to concentrate on their education requirements.

While feedback from participating schools and colleges, teachers and young carers identifies the significant benefits of our engagement, including school retention, the number of schools that our young carer team engages with is limited by the amount of the Young Carers program funding.

To improve identification of children and young people in primary and secondary education to assist schools and colleges can appropriately support young carers to improve their education and future employment outcomes Carers ACT recommends that the ACT Government:

- Encourages all primary and secondary public schools in the ACT to include a mechanism for students and families to identify their caring status in enrolment documents, similar to that implemented by Gungahlin College
- Consult with young carers, caring families, educators and with relevant organisations, including the ACT Council of Parents & Citizens Council, to co-design a strategy to improve identification of and support for young carers, including referral to specialist young carer services
- Continues to support the Young Carer Programs and invests sufficient funds to increase the reach of this program to support ACT young carers.

Unique factors for youth suicide in the ACT

A unique factor for youth suicide is its proportion of young people compared with other Australian states and territories. While the ACT has the third highest proportion of its population aged 0-19 years (behind the Northern Territory and Queensland) it also has the highest proportion of young people in Australia in the age cohorts 15-29 years. This is attributed to young people relocating to Canberra for higher education or employment opportunities.[14]

Our submission addresses concern about the effect of relocation upon mental health as well as the difficulties facing young carers entering tertiary education or seeking a career path.

Relocation can cause a sense of anticipation and achievement, but it can also contribute to mental health risk factors – a sense of isolation because of reduced contact with and support from close

[13] Youth Coalition of the ACT (2015) *Mental Health Perspectives of Young People Aged 12-25 in the ACT* at https://members.youthcoalition.net/sites/default/files/documents/Mental%20Health%20Perspectives%20of%20Young%20People.pdf

[14] Australian Bureau of Statistics (2012), *Population by Age, Sex and Regions of Australia 2011*. Available at http://www.abs.gov.au/ausstats/abs@.nsf/Products/3235.0~2011~Main+Features~Australian+Capital+Territory?OpenDocument

family and social networks; and additional living costs, such as accommodation and transport that can contribute to increased anxiety and financial and housing stress. Young carers are also at risk of not completing tertiary education or not remaining in the paid workforce for similar reasons discussed in '*Young carers at risk of suicide'* above.

These young people may be reluctant to disclose this to new friends or colleagues if they are experiencing anxiety, depression or another mental health issue because of past or perceived stigma or discrimination or fear of damaging these new relationships

Students attending higher education providers may have access to on campus student counsellors and general practitioners; however some may be reluctant to seek help from student clinics or counselling services. This could be due to perceived potential discrimination by tutors or lecturers impacting on their academic outcomes or employment prospects or simply a strong desire for self-care. University students also report a lack of information about other mental health services in the ACT or nearby GPs, or the cost of medical consultations and medication, which become barriers to seeking help to manage their mental health issues. This is particularly true of our growing international student population that may experience increased alienation from the mental health services available to them.

Similar barriers about disclosing anxiety, depression or mental health issues may be experienced by young people who have moved to Canberra for employment, and who are also seeking to establish their career or create new friends and professional networks.

To support young carers in tertiary education or in employment and young people relocating to the ACT for study or employment Carers ACT recommends that the ACT Government:

- Invests in an awareness campaign about youth suicide and self-harm prevention to encourage universities and other training institutions to provide information in student orientation resources, or student media about free or bulk billing mental health services in the ACT as an alternate to student medical or counselling services, including contact details, location and bus routes if necessary
- Consult with and support ACT government agencies and non government organisations, such as the Canberra Business Chamber and the Master Builders of the ACT, to design strategies to assist ACT businesses identify and support young people with risk factors of youth suicide and self-harm
- Co-design youth suicide and self-harm prevention strategies with universities and other training institutions to reduce the risk of suicide and self-harm, including the Canberra Institute of Technology to reduce the risk to young people undertaking courses in the construction sector and other sectors with a known increased risk of suicide
- Review existing child, young people and health frameworks to include strategies to identify and support this group vulnerable to increased risk of suicide and self-harm
- Invest in research to identify suicide and self harm triggers in ACT young people and implement strategies to address these (this research could complement the current research about suicide undertaken by the ACT Health Directorate).[8]

Summary of Recommendations

Carers ACT provides the following recommendations to the inquiry;

1. To determine more accurate ACT data on suicide and self-harm; develop an evaluation of prevalence and service need
2. Improve the capacity of evidence-based, best practice interventions in the ACT to decrease waiting times and make responses timelier.
3. Comprehensive mental health literacy training for medical professionals including general practitioners, specifically looking into understanding self-harming and suicidal behaviours and planning comprehensive treatment plans.
4. Increasing the availability for high quality online therapies such as CBT at no cost for young people as an early intervention strategy.
5. Provide more assertive case management of care plans; understanding that this is a group that has difficulty engaging with mental health services.
6. Encourage all primary and secondary public schools in the ACT to include a mechanism for students and families to identify their caring status in enrolment documents, similar to that implemented by Gungahlin College
7. Consult with young carers, caring families, educators and with relevant organisations, including the ACT Council of Parents & Citizens Council, to co-design a strategy to improve identification of and support for young carers, including referral to specialist young carer services
8. Continues to support Young Carer Programs and invests sufficient funds to increase the reach of this program to support ACT young carers.
9. Invests in an awareness campaign about youth suicide and self-harm prevention to encourage universities and other training institutions to provide information in student orientation resources, or student media about free or bulk billing mental health services in the ACT as an alternate to student medical or counselling services, including contact details, location and bus routes if necessary
10. Consult with and support ACT government agencies and non-government organisations, such as the Canberra Business Chamber and the Master Builders of the ACT, to design strategies to assist ACT businesses identify and support young people with risk factors of youth suicide and self-harm
11. Co-design youth suicide and self-harm prevention strategies with universities and other training institutions to reduce the risk of suicide and self-harm, including the Canberra Institute of Technology to reduce the risk to young people undertaking courses in the construction sector and other sectors with a known increased risk of suicide
12. Review existing child, young people and health frameworks to include strategies to identify and support this group vulnerable to increased risk of suicide and self-harm
13. Invest in research to identify suicide and self-harm triggers in ACT young people and implement strategies to address these