

22 December 2016

Treasurer
ACT Legislative Assembly
GPO Box 1020
Canberra City ACT 2601

Carers ACT 2017-18 ACT Budget Submission

Carers ACT appreciates the opportunity to respond to the ACT Government's invitation to comment on priority commitments for its 2017-18 Budget.

Carers ACT is the ACT peak body representing the diversity of Canberrans who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged.

There are around 48,500 unpaid, family and friend carers in the ACT, who are an integral part of our aged, health and disability systems. Deloitte Access Economics estimated carers provided 1.9 billion hours of unpaid care in 2015. The estimated replacement cost of this care with formal care services was \$60.3 billion.¹

Carers ACT response to the ACT Government's invitation includes three priority areas for funding commitments in the 2017-18 ACT Budget:

Recommendation 1

That the ACT Government continues its investment to support ACT carers and commits ongoing funding in the 2017-18 ACT Budget and forward estimates to 2019-20 to implement priority actions in the ACT Carers Strategy.

Recommendation 2

That the ACT Government invests in the implementation of a Respectful Relationships Program to be delivered in ACT High Schools through a Carers ACT and Youth Coalition of the ACT collaboration.

Recommendation 3

That the ACT Government invests in the development of an LGBTI (Lesbian, Gay, Bisexual, Transgender and Intersex) Carers Program to support carers, caring families and LGBTI people in the ACT.

1. Implementation of the ACT Carers Strategy to support ACT carers

Carers ACT welcomes the ACT Government's funding commitment for Carers ACT to jointly develop an ACT Carers Strategy in partnership with the ACT Government.

¹ Deloitte Access Economics (2015) *The economic value of informal care in Australia*, 2015 for Carers Australia, Canberra.

Joint development of this strategy is expected to begin early in 2017, and is an agreed priority and outcome in the Parliamentary Agreement for the 9th Legislative Assembly for the Australian Capital Territory:

“PA 7. Making our community even stronger and more inclusive

ACT Labor and the ACT Greens understand that government has an active and positive role to play in making sure everyone in our community is supported, welcomed, and has the opportunity to reach their full potential. The parties therefore agree to:

1. Develop a carers strategy in close consultation with Carers ACT, disability groups and other affected community members ... “

An ACT Carers Strategy is important and timely because of the major reform in aged and disability community services that focus on consumer directed care and the recognition that carers and their needs can be ignored or forgotten by service providers.² This lack of recognition occurs even though evidence indicates that carer-focussed support and recognition has a positive impact on carers wellbeing.³

Once developed and implemented the ACT Carers Strategy will provide a strategic framework for the ACT Government, government agencies, and government-funded private and not for profit organisations to recognise, support and improve outcomes for ACT carers.

The *An ACT that Cares for Carers* booklet was developed as the centre of the Carers ACT 2016 ACT Election Campaign. Its suggested priority areas reflect what ACT carers have told us they need to support their caring role, and outcomes of carer and stakeholder consultations by other Australian governments to develop their carers strategy. The suggested priority areas are:

Priority Area 1: Increased identification, community awareness and information

Priority Area 2: Inclusion as partners in care

Priority Area 3: Increased employment and education participation

Priority Area 4: Improved health and wellbeing

Priority Area 5: Improved evidence base

Carers, government agencies and other organisations will be consulted during the development of the ACT Carers Strategy and these suggested priority areas may change to reflect identified needs during consultations.

To achieve improved outcomes for carers and caring families a funding commitment by the ACT Government over its term of government is necessary to implement the priority areas in the carers strategy.

Recommendation 1:

Carers ACT recommends that the ACT Government continues its investment to support ACT carers and commit ongoing funding in the 2017-18 ACT Budget and forward estimates to 2019-20 to implement priority actions identified in the ACT Carers Strategy.

2. Respectful Relationships Program in ACT High Schools

The ACT Parliamentary Agreement identifies the concern of the ACT community to continue social and emotional learning programs in schools to enhance the skills of children and young people to engage in

² The recent Carers ACT *NDIS and Carers Survey* found that 80 per cent of respondent carers' needs were not considered in the development of the NDIS participant's support plan, even though identification of their needs and their capacity to continue to care are to be part of the NDIS planning process. The final survey report is still to be published.

³ Cummins Robert A et al (2011) *Carers counselling intervention study*, Deakin University, Geelong.

respectful relationships, including to prevent violence and sexual assault. (See Parliamentary Agreement 2.4 Social and emotional learning programs in schools.)

Carers ACT currently delivers a respectful relationships program within schools across the ACT. The action research project, *We All Care – Young People and Domestic Violence*, is funded under the Building Safe Communities for Women national initiative. Funding for the project ceases in December 2017.

The workshop-based project utilises some objectives of the Love Bites program.⁴ Two Carers ACT staff delivering the *We All Care* project have received Love Bites facilitator training. Five high schools across the ACT are or will be participating in the project before funding ceases.

The We All Care project

The *We All Care* project was designed following Carers ACT's consultation with young carer focus groups that identified they experienced stigma, and bullying from other students; discussions with several ACT High Schools with a young carers support coordination program; Carers ACT's Young Carer Coordinators and our carer support staff, including counsellors. It recognises that domestic or family violence impacts on all family members, and that many students experience discrimination, and bullying or harassment from peers or they may exhibit this behaviour.⁵ Young people also experience violence in their homes.

Consultations indicated that the issue of respectful relationships supported by respectful communities was an issue across all young people and a way of reducing violence in relationships amongst adolescents and as an early prevention activity to reduce family violence.

We All Care aims to:

- raise awareness about power relations and how to access help if bullying or harassment occurs, including online bullying
- break down attitudes about power relations
- build skills to negotiate non-violent and respectful relationships
- support young people to create a respectful school environment
- create a safe environment for young people to share their opinions about and experiences of violence and harassment
- encourage acceptance of diversity, including cultural, gender and physical and mental disability among students, teachers and other school staff.

Both a male and female facilitator deliver the project to model respectful relationships between male and female students, teachers and other school staff.

Young people participating in the workshops are supported to become a Respectful Relationship Champion to provide ongoing respectful relationships modelling and be a mentor for other students in their high school. They are also supported to identify projects and activities within the school that use a community development and youth leadership approach to creating safe environments.

Carers ACT recommends that the ACT Government invests in the development of an ACT Respectful Relationships program to be delivered initially in ACT High Schools through a Carers ACT and Youth Coalition of the ACT collaboration. Both organisations have extensive experience working with young people and

⁴ See <http://napcan.org.au/our-programs/love-bites/#a33>

⁵ Carers ACT has been invited to deliver *We All Care* workshops in 2017 by an ACT High School that is concerned about a group of students exhibiting this behaviour.

within school environments to raise awareness of issues concerning young people and providing services or service referrals for young people.⁶

The Respectful Relationships collaboration will consult with organisations supporting young people in schools, including the ACT Education Directorate and the Safe Schools Coalition, to design and deliver an ACT program that complements best practice standards for education programs and the priorities in the *ACT Children and Young People's Commitment 2015-2025*.⁷

As part of the national initiative, Carers ACT's *We All Care* project regularly meets with ANROWS (Australia's National Research Organisation for Women's Safety) to review and evaluate the project's progress. These outcomes will also inform the design of the proposed respectful relationship program.

The proposed Respectful Relationships Program would deliver these outcomes:

- Consultation with the ACT Education Directorate, Safe Schools Coalition and other organisations on the proposed ACT Respectful Relationships Program
- Review of the Carers ACT *We All Care* project and other respectful relationship programs to identify best practice principles to guide the proposed ACT Respectful Relationships Program
- Development of an ACT Respectful Relationships Program education module for review by educators and other stakeholders
- Training of male and female facilitators to deliver the program in selected ACT High Schools
- Selection of high schools to participate in the first delivery of the ACT Respectful Relationships Program, including an audit of selected high schools to identify their readiness for program delivery
- Evaluation of the first year's delivery of the proposed program and modification of the ACT Respectful Relationships Program education module as required.

Recommendation 2:

Carers ACT recommends that the ACT Government invests in the implementation of a Respectful Relationships Program to be delivered in ACT High Schools through a Carers ACT and Youth Coalition of the ACT collaboration.

3. LGBTI (Lesbian, Gay, Bisexual, Transgender and Intersex) Carers Program to support LGBTI carers, and carers of LGBTI people

The ACT Government has an LGBTIQ Ministerial Advisory Council and there are ACT organisations that specifically support LGBTI⁸ community members, but there is little recognition of the specific support needs of LGBTI carers or carers of people identifying as LGBTI who require support to live in the community because of ageing, disability or mental health issues.

Culturally sensitive resources and support for LGBTI carers, LGBTI people and their families has been a concern for Carers ACT and the National Network of Carers Associations. In response, Carers ACT and the network have advocated for recognition of, and inclusion of LGBTI carers and carers of LGBTI people in key government policy frameworks and program delivery. While some Carers Associations have received funding to develop LGBTI inclusive resources, there are no ACT LGBTI carer specific resources.

⁶ See www.carersact.org.au and <http://www.youthcoalition.net/> for more information about Carers ACT and its young carer program, and the Youth Coalition of the ACT respectively.

⁷ ACT Government (2015) *The ACT Children and Young People's Commitment 2015-2025*. Accessible: http://www.communityservices.act.gov.au/__data/assets/pdf_file/0008/798785/CSD_CYPC_A4_web.pdf

⁸ Carers ACT is using the term "LGBTI" in this submission, but is aware that the ACT Government's Ministerial Advisory Council includes "Queer" in its title, as do other organisations. Including "Queer" in the LGBTI acronym can cause concern for older LGBTI people. Other organisations also use "Q" to reflect that some people are "Questioning" their gender identification. We are also aware that many transgender and intersex people do not identify as gay, lesbian or bisexual.

The challenges of LGBTI carers, LGBTI people and their families is outlined in the 2015 research, *An Extra Degree of Difficulty*⁹. Carers ACT was a member of the research advisory group for this project along with the Australian Research Centre in Sex, Health and Society, La Trobe University, Val's Café and Carers Australia.

LGBTI carers

Lesbian, gay, bisexual, transgender diverse and intersex people in care relationships include carers who identify as LGBTI and carers of LGBTI people. LGBTI carers look after a range of people with a variety of care needs. They often take on a caring role for friends and 'family of choice' as well as their biological family.

They also face many of the same pressures as any other carer. However, they may also experience specific challenges related to:

- a lack of recognition by service providers of a person's experience, identity, relationships and caring role that can add additional stress to their caring role
- discrimination from service providers for their own support or when seeking support for the LGBTI person they care for

These specific challenges can prevent LGBTI carers accessing services for the person they support or to maintain their own caring role.

Findings from the Australian Research Centre in Sex, Health and Society research, which included ACT LGBTI carers or carers of older LGBTI people, revealed older LGBTI carers and carers of LGBTI people:

- are more likely to be carers and rely on intimate partners and friend carers
- care for partners who are fearful of discrimination in accessing formal care
- care for biological family members who are homophobic
- experience an adverse impact on their health, wellbeing and relationships
- need social support, peer support and respite
- need recognition of their experiences of loss and grief
- want LGBTI specific support groups (as heterosexual carers in carer support groups didn't always understand the issues they face many research participants withdrew from these carer support groups)
- want services that are inclusive of LGBTI carers and carers of older LGBTI people.

There is limited research about other LGBTI carers in Australia, particularly relating to young LGBTI people. Carers Victoria is delivering a Young LGBTIQ Program that includes an online resource to help service providers support young LGBTIQ people. This eLearning resource was informed in part by a 2015 Young LGBTIQ carer survey completed by Victorian young people who identify with a diverse range of gender identities and sexualities.¹⁰

⁹ See *An Extra Degree of Difficulty* report and evidence-based guide on experiences and needs of older GLBTI carers and of older LBGBTI people. Accessible:

<http://www.carersvictoria.org.au/Assets/Files/An%20Extra%20Degree%20of%20Difficulty.pdf>

¹⁰ See <http://www.carersvictoria.org.au/how-we-help/young-carers/young-queer-and-caring/>

The *Gender Diversity in the ACT – A survey of Trans Experiences* report¹¹ doesn't identify caring responsibilities, but findings suggest that respondents face similar issues experienced by LGBTI carers in identification, accessing services and social engagement.

The age of respondents in this research conducted by A Gender Agenda also reflects younger age groups than the above research on older LGBTI carers. The majority of respondents were aged 25 to 44 years, 30 per cent were under 25 years and 19 per cent were aged 45 to 64 years.

Research findings indicate:

- a lack of social engagement with family and the broader community
- 68 per cent of respondents were not in a relationship
- transgender people are half as likely to be in an intimate relationship and more than twice as likely to live alone
- respondents were more likely to rely on the internet for information about gender-related issues, although some relied on trans support groups
- 68 per cent of respondents with partners rated information and support for their partner as being highly important
- 61 per cent of respondents indicated that it was very important for them to access information for family and friends
- 50 per cent of respondents had accessed psychological or psychiatric or counselling services, but only 7 per cent indicated that had obtained support from a counsellor or other mental health provider.

One respondent commented:

Gender issues seem to be lumped in to the GLBTI category, which seems to focus mostly on the GL issues, and ignore the BTI. Homosexuality has become socially acceptable in recent times, even though there is still discrimination, but trans- and intersex issues still seem taboo.

Recent media reporting of transgender identification has also raised awareness of transgender issues particularly for children and young people and their caring families.

Carers ACT has noticed an increase in the number of carers we support because a child or family member has a mental health issue or a chronic condition seeking support from Carers ACT for a transgender child or young adult. The transgender child or young adult may also be supported by a parent (carer) because of an existing health or disability issue, such as a mental health issue or Autism Spectrum Disorder.

Carers ACT Advocacy for carers of transgender children or young adults examples

1. An ACT carer sought support from Carers ACT as an advocate when their transgender young adult child was seeking for an ACT tertiary organisation to include additional gender identification in enrolment and other student documents.
2. An ACT carer sought Carers ACT support when their transgender young adult was negotiating with an employment agency not to identify their transgender status to potential employees. The carer and young adult were concerned about discrimination by employers and work colleagues, and the apparent breach of the young adult's human rights.

¹¹ A Gender Agenda (2011) – *A survey of Trans Experiences – A survey of Trans Experiences* Accessible: http://genderrights.org.au/sites/default/files/u43/Gender_Diversity_in_the_ACT.pdf. Note: this research included sexually gender diverse people as well as transgender people.

3. Another ACT carer sought advocacy support from Carers ACT when their transgender family member was a patient in a mental health unit and was denied their hormone therapy. In this situation Carers ACT became the advocate for the transgender patient when the parent (carer) was unable to do so.

Carers ACT believes that an initiative to support LGBTI carers and carers of LGBTI people in the ACT would complement the activities of other ACT organisations supporting LGBTI people and strengthen the LGBTI community and service delivery.

The proposed LGBTI Carers Program to support carers and carers of LGBTI people would deliver these outcomes:

- Provision of evidence-based policy advice to the ACT Government, including outcomes of the LGBTI carers program
- Delivery of support groups to LGBTI carers and carers of LGBTI people
- Delivery of advocacy services to LGBTI carers and carers of LGBTI people
- Support for LGBTI carers and their families to navigate age, disability and mental health services through appropriate referrals to LGBTI sensitive organisations¹²
- Increased connectivity for LGBTI carers, carers of LGBTI people and organisations in the ACT supporting LGBTI people.

Recommendation 3:

Carers ACT recommends that the ACT Government invests in the development of an LGBTI (Lesbian, Gay, Bisexual, Transgender and Intersex) program to support carers, caring families and LGBTI people through:

Please contact Colleen Sheen, Senior Policy Advisor Carers ACT if you need further information on 6296 9900 or colleen.sheen@carersact.org.au

Yours sincerely



Lisa Kelly
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¹² These services also include the Commonwealth Respite and Carelink Centre, and mental health specific respite, carer counselling and a young carers program delivered by Carers ACT. Some Carers ACT staff identify as LGBTI and, or have lived experience of LGBTI family members or friends.