



ADACAS

A D V O C A C Y

ADACAS ACT Budget Submission 2023 - 24

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1. About ADACAS and Advocacy

The ACT Disability Aged and Carer Advocacy Service (ADACAS) is a human-rights focussed organisation, which provides:

- Individual advocacy for and with people with disability, people experiencing mental ill health (or psychosocial disability), older people, and carers.
- Delivering the Federal Government's National Disability Advocacy Program and National Aged Care Advocacy Program in the ACT.
- Assistance with National Disability Insurance Scheme (NDIS) related appeals to the Administrative Appeals Tribunal
- Redress Scheme support services to people who are survivors of institutional child sexual abuse
- My Aged Care, Care Finder services older people seeking assistance to understand and navigate community and residential aged care services.
- Systemic advocacy and engagement designed to contribute to improved systems, policies and procedures that impact on the experience of the cohorts with whom we work.
- Building Employer Confidence program which supports employers to increase their capacity to successfully employ people with disabilities
- Supported Decision Making program and services to young people to increase their capacity and reduce the need for guardianship.

Advocacy is about **protecting the human rights and improving the wellbeing of some of the most vulnerable people/others in the most challenging of circumstances in the ACT community.** Advocates focus on advocacy topics identified by each person as having negative impacts for them, and work in tailored and constructive ways with that person, their family/friends and other stakeholders as needed, to progress feedback/ find resolutions/ seek to ensure the person's rights are upheld in challenging situations. ADACAS offers issues-based non-legal advocacy, and the topics of advocacy are multiple and varied, ranging from housing, to access to justice, to psychiatric treatment order hearings, to quality-of-service issues, to child protection processes, to restrictive practice/ restraint/ seclusion, to substitute decision-making, to aged care service issues, to NDIS and NDIS appeals etc. The majority of ADACAS' focus is on advocacy, with the majority of the service focussed on individual advocacy (support for a particular person, with a particular issue).

Advocacy is also a **safeguard** working to improve experiences of people from some of the specific groups whose wellbeing outcomes are to be measured under the ACT Wellbeing Framework: people with disability, older Canberrans and carers (including those with intersectional life experiences).

ADACAS additionally has over time delivered projects to embed supported decision-making approaches in service systems and explores practical responses to issues arising through individual advocacy and supported decision making.

The **ACT Wellbeing Indicators** highlight the need for people to feel like their voices are heard, for trust to be built and for restorative practices to occur. Individual advocacy support can directly contribute to wellbeing: it can enable the voices of people with disability, older Canberrans and carers to be heard, and encourage restorative experiences in situations where things have gone awry.

ADACAS also emphasises the **importance of addressing the compounding impacts of intersectional disadvantage**. ADACAS already works with people with disability, people with mental ill health, older people, and carers, who are additionally Aboriginal or Torres Strait Islanders, from a Culturally and Linguistically diverse background/s and/or from LGBTQI+ populations. Individual advocates working with people with these intersectional experiences, there is the potential to achieve outcomes that **improve wellbeing across multiple of the specific groups being monitored under the ACT Wellbeing indicators, simultaneously**.

Finally - **Independent advocacy is an excellent economic investment**. A cost benefit analysis conducted in 2017 (and reviewed and affirmed in 2020/21) by independent academics demonstrates that for each \$1 invested in individual disability advocacy, that there is \$3.50 in benefit¹.

ADACAS is a member of DANA, the Disabled Persons Advocacy Network, and OPAN, the Older Persons Advocacy Network.

ADACAS is based in Canberra and has been providing free individual advocacy in this region for over 30 years. More recently, ADACAS has been funded to deliver individual advocacy for people with disability across regions of NSW.

Acknowledgement of country

ADACAS acknowledges the language groups and Traditional Owners of the various lands on which we work, including:

- the Ngunnawal communities for our work in the Canberra area,
- the peoples from Aboriginal communities for our work across the South-Eastern corner of NSW from the Illawarra to the Victorian Border and the NSW Coast to the Murrumbidgee Region.

We pay our respects to their Elders, past present and emerging and to all Aboriginal and Torres Strait Islanders in our communities. Sovereignty was never ceded.

2. Introduction

ADACAS appreciates the opportunity to contribute as part of consultations about the ACT government priorities for the 2023-24 and future budgets.

As part of the wellbeing framework, there is a recognition of the need to be responsive to **diversity, and wellbeing across the community**, with the **following population groups identified** as ones on which the ACT government is measuring wellbeing outcomes: Aboriginal and Torres Strait Islander Peoples, Carers, Children and Young People, Culturally and linguistically diverse people, Women (a gender lens), LGBTIQ+, Older Canberrans, People with disabilityⁱⁱ.

Whilst universal actions (to benefit the entire community) may absolutely benefit many of these groups, it is important that the ACT government also ensure **funding is being adequately targeted specifically to address needs of the identified populations** (as listed above) with a view to unmet needs being addressed (e.g. In addressing housing/homelessness, violence response prevention, healthcare, justice etc) and in terms of human rights being adequately upheld.

In the ACT, there are approximately 80,000ⁱⁱⁱ people with disability and over 50,000^{iv} (informal/non-paid) carers. Before the pandemic, it was estimated that 1 in 5 people experience mental ill health in each year^v – for a territory with a total population at approximately 430,500^{vi}, this would be equivalent to over 86,000 people. The impact on mental health of the community during the pandemic has been widely published. There are over 50,000 older people living in the ACT^{vii}. Across Australia, half of all people over the age of 65 in Australia have a disability^{viii}.

As a human rights jurisdiction, with a stated focus on wellbeing – it is important that **wellbeing and needs especially of those people in the most difficult of circumstances, is being adequately responded to**. This must explicitly be **inclusive of the wellbeing and needs of people experiencing intersectional disadvantage**, such that everyone, inclusive of humanity in our full diversity* have their rights upheld, and equitable access and quality of support. *Including but not limited to all the populations named in the ACT Wellbeing Framework, no matter what combination of intersectional identities/ life experiences people bring.

We emphasise also the benefits of **prevention, of early identification and of early support**. When we talk early support: we mean **early in terms of when an issue (or theme) arises** – no matter the age of those involved. Whether this be in relation to early identification and support around disability, early support in terms of onset of mental ill health, prevention around homelessness etc.

All of us should have **equitable access and equitable quality of services, proportionate to need**. All of us also should have access to supports provided in ways that take account of **trauma informed practice, restorative practice principles**, and **uphold human rights**.

3. Budget Priorities

3.1 Individual Advocacy

In 2004 the ACT became the first jurisdiction in Australia to enact a Human Rights Act. Both current and former ACT Governments can be rightly proud of this record. As we celebrate the 20 year anniversary of ACT becoming a human rights jurisdiction, it is vital that the ACT Budget 2023-24 reflect an ongoing commitment to allocating sufficient resources to uphold all Territorians' human rights.

In order to enact many of their rights that are detailed in the ACT Human Rights Act 2004, many people need additional supports to have their voices heard. Key amongst those supports are Individual Advocacy Services for the most vulnerable citizens. Individual Advocacy supports people to achieve wellbeing outcomes in every single wellbeing domain in the ACT Wellbeing Framework. Supporting clients to resolve issues falling under the domains of Housing and Home, Education and life-long learning, Health, Living standards, Governance and institutions, Safety and Economy is ADACAS' core business. We have been achieving successful outcomes in these areas for over 30 years.

3.1.1 Individual Advocacy – meeting demand.

ADACAS has seen a significant increase in demand for advocacy services, covering issues including housing, education, child protection, discrimination, guardianship, health care, access to community services and matters relating to the NDIS.

There has also been an increase in the complexity and intersectionality of issues and whilst ADACAS takes a human rights focus dealing with individual issues, there are many times that multiple issues need to be addressed simultaneously to achieve an outcome that sees the expressed wish of the client being upheld. Advocates consistently manage a clients dignity of risk when dealing with many complex matters.

ADACAS is proactive in meeting vulnerable community members where they reside and frequently visit closed mental health and justice settings. There is a definite need to be able to increase this to the wider health and justice system and to inform staff across facilities how advocacy is a safeguard for vulnerable people.

ADACAS also takes a proactive approach to support people when their rights have been violated. The recent breach of personal information relating to residents of the Dhulwa Secure Mental Health Unit highlights that there are still significant threats to human rights of the most vulnerable people in the ACT.

3.1.2 Justice Advocacy

ADACAS' expertise and knowledge from a systemic perspective as well as individual advocacy services are being sought by more people having interactions with the justice system. This includes people working in the justice system as well as detainees in the Alexander Maconochie Centre who ADACAS provides services through on-site in-reach into the Centre.

In order to uphold the rights of all people to fair and equitable treatment before the law, it is imperative that all vulnerable people seeking individual advocacy support have access to that service. This would complement and amplify the impact of the work that Disability Liaison Officers are doing across many justice settings, it was also identified in the Towards' Disability Justice report that there is a need for **further individual advocacy** to be available for people with disability^{ix} (with which we include psychosocial disability).

There are specific areas within the ACT Courts where the need for individual advocacy has been identified and so additional resources to meet this need is welcome.

This will enable barriers to be addressed, information and support to be arranged, and help prevent emerging concerns. Advocacy can also serve an important role to assist people in communicating their needs and situations when seeking legal advice, and in assisting to seek to divert people from entering the justice system.

3.1.3 Health Advocacy

Demand for advocacy services from people in hospital has also increased and we are aware that many people who contact us following involvement with the hospital system are not having their rights and wishes respected. We believe there is a distinct benefit in having advocacy services for these people available in a more timely manner, through providing outreach routinely at all ACT public hospitals and facilities as this will increase the safeguards available to people and support the ACT Government in its endeavour to be a human rights jurisdiction, and therefore limiting circumstances that led to their rights being violated. This will have the added advantage for the hospital system of increasing client satisfaction and increasing client wellbeing.

ADACAS measures client wellbeing using the SCORE framework measured both at the outset and conclusion of each advocacy case. Our results show significant improvement across all SCORE domains, including wellbeing for the clients we support.

The addition of an Advocate providing outreach support and information to people across health facilities will lead to greater understanding of the needs of people with disability and ensuring the expressed wish of older people are heard by health professionals and by the general community across the health system, will positively influence all six indicators in the ACT Wellbeing Framework for the most vulnerable clients.

3.2 Supported decision-making

Having a sense of autonomy in your life: being able to make decisions about your own life, and have those decisions heard and respected, is fundamental to every domain within the ACT Wellbeing Framework.

Supported Decision-Making (SDM) is for people who may need support to make decisions if their decision-making capacity is impaired for example, due to disability, mental ill health or cognitive decline. It seeks to enable people to maximise their participation in decision-making, have their rights, will and preference respected, engage with dignity of risk, and exercise choice and control^x. At the present time, whilst some people have access to support for decision-making via family, friends or formal/informal networks, many people with disability (of all ages) and older people do not have access to such support.

Access to support for decision-making is a human right, as outlined in the United Nations Convention on the Rights of Persons with Disabilities which enshrines the principle of “equal recognition before the law”^{xi}, and requires Australia (and other UNCRPD signatories) to ensure people with disability have access to the support they require, to exercise their legal capacity on an equal basis with others^{xii}.

The Australian Law Reform Commission report Equity, Capacity and Disability in Commonwealth Laws (Australian Law Reform Commission, 2014)^{xiii} (and many reports since) have recommended a shift away from substitute decision making models (such as guardianship, power of attorney etc) towards supported decision-making approaches which respect a person’s will and preference^{xiv}.

We strongly encourage the Government to fund greater support to people who are interested in and / or need **independent supported decision making**. **There is a need to fund assistance for** people in need of decision support who are

- interacting with the justice system, or
- needing to make complex healthcare or complex other decisions, or
- Living in closed settings such as mental health wards, residential aged care, disability supported independent living settings and more.

ADACAS strongly supports **initiatives to focus on working to support and strengthen decision making skills and building capability of individuals and confidence in support networks** to limit the need for substitute decision-making arrangements such as guardianship or enduring power of attorney (EPOA).

ADACAS has consistently highlighted the importance of improving structures to uphold decision-making rights of people in the ACT that need this support. We commend the ACT Government for changes made in the Guardianship and Management of Property Bill 2022 that embed the use of Supported Decision Making to the appointment of, and decisions by, guardians and managers. This change will ensure that some of the most vulnerable Territorians will be able to make and express their own decisions in exercising control over their own affairs, lives and bodies. In order to ensure the intent of the legislation is realised, however, it will be necessary to **adequately resource organisations capable of providing Supported Decision-Making services to meet** the inevitable, and desirable, **increase in demand** they will experience. ADACAS is one of the key organisations with the skillset to deliver on this service.

In many situations, for a person with decision support needs to have their rights adequately upheld, there is a **vital need for independent external support for supported decision making**, especially in relation to complex decisions. In relation

to SDM - ADACAS staff work with a model of supported decision making which: “assumes different roles for already existent members of a person’s network; provides training to this group and the person; and activates the relevant network role where necessary”^{xv}. Whilst family/friends can be part of a support network in supporting decision making, in some instance the nature and/or the complexity of the decision, means that family/friends have conflicting interests, and/or are not always placed to assist. Decision support needs can vary decision to decision^{xvi}.

3.3 Disability Strategy

ADACAS supports the Government’s efforts to develop strategies to support the wellbeing and uphold the rights of Territorians living with disability. These include the **ACT Disability Strategy, the Disability Justice Strategy and Disability Health Strategies** as mechanisms to achieve positive systemic change. Ongoing commitment of resources, time, attention and accountability will be important to achieving the goals outlined in each of these strategies. Without these commitments the rights of people living with disability stand to be consistently disregarded.

3.3.1 Disability Health Strategy

The ACT Government commitment to a **Disability Health Strategy**, has the potential to significantly improve the experience of people with disability (of all ages) interacting with health systems across the ACT. We call upon **both design and implementation to be fully and comprehensively funded**, and for all work to take careful consideration of how to remedy structural exclusion and discrimination, as well as intersectional barriers and diverse needs.

We encourage continued shared work across community and all levels of government to **resolve the multiple complex barriers meaning that there are people with disability and older people are living in hospital beyond when acute care is needed**. We note especially the added value that individual advocacy can bring to these situations in working together with the person at the centre of the circumstance, informal family carers, and health staff to ensure that the rights of individuals are upheld. Funding needs to continue for **health-related advocacy and implemented for supported decision-making on health** matters as this would both provide important information and insights about the challenges that exist whilst also ensuring that people for whom the systems are not currently working, have support in having their individualised needs met. As well as directly supporting outcomes in the health domain of the ACT Wellbeing Framework.

3.3.2 Disability Justice Strategy

With the conclusion of the First Action Plan 2019-23 ADACAS looks forward to supporting the development of a Second Action Plan to deliver the **ACT Disability Justice Strategy 2019-29**. Whilst the achievements of this strategy to date are important, there continues to be much more change needed to ensure that people with disability (in their full diversity) are having their rights adequately and consistently upheld in interacting with justice systems (whether as victim survivors / offenders or witnesses). We call upon the ACT Government to adequately resource actions identified in the Second Action Plan, once it is developed. This will support outcomes in the Safety domain of the ACT Wellbeing Framework.

ADACAS also highlights the need for **additional legal funding** to enable people to access the legal assistance that is needed in different situations^{xvii, xviii}.

3.4 First Nations People.

ADACAS supports the continued calls from Aboriginal and Torres Strait Islander organisations for **urgent action to both formally inquire into, and to address the unacceptable levels of, over-representation of Aboriginal peoples in the ACT Justice system.**

ADACAS also highlights the continued importance of all governments and communities acting together to respond urgently to unequal health outcomes/life expectancies being experienced by **Aboriginal and Torres Strait Islander people**, in line with the *National Agreement on Closing the Gap*^{xix}. We also particularly also highlight the need to take account of the **specific needs of Aboriginal and Torres Strait Islander people with disability**. Research conducted by the First Peoples Disability Network show that “Disability in Aboriginal and Torres Strait Islander communities is twice as prevalent, more complex in terms of co-occurring disabilities, and compressed within a shorter life expectancy compared to other Australians”^{xx}, highlight the cumulative toll, and the importance of addressing the intersectional discrimination and health inequalities that are occurring, and which are resonating across many domains of life and wellbeing^{xxi}.

3.5 Housing and homelessness

3.5.1 Increase social and community housing stock

Housing is a necessity and can be foundational in enabling other aspects of wellbeing to occur (having a house can support improved wellbeing outcomes in relation to health, economy, education, living standards, safety, and identity and belonging (to name a few). Accessible, affordable, safe, and suitable housing must be available to everyone.

We welcomed Chief Minister Andrew Barr’s calls to successive Commonwealth governments to waive historic housing debt and in seeking to reinvest millions in saved interest towards “building more social and affordable housing in the ACT”^{xxii}. We call on the ACT government to continue to work with all stakeholders towards significantly increasing the amount of social and community housing stock in the ACT that is universal design and to a level that meets the needs of the ACT community. We strongly encourage investment also in prompt and ongoing maintenance of properties, to ensure people are living in homes that are in good condition.

We highlight also the need to revamp/renew the emergency and crisis housing options, such that they can meet the diverse housing needs of people in situations where emergency or crisis options are required.

As well as directly supporting the Housing and home wellbeing domain, increased supply of public housing supports several other domains in the ACT Wellbeing Framework including Economic participation, Identity and belonging and Safety.

3.5.2 Housing accessibility

ADACAS encourages **continued work in embedding universal design in housing, across the community**. All people should be able to have a home, that meets their needs, but also be able to easily visit family/friends without concerns as to whether the home is an accessible location. Building accessible properties allows for ageing in place, as well as meets the needs of people with a disability and the broader community. We encourage also going beyond the minimum standards now contained in the National Construction Code 2022 to Livable Housing Design Guidelines Levels gold, and platinum where possible. We also especially encourage efforts to consider accessibility inclusively (not solely in terms of physical accessibility, but also what accessibility might mean for people with sensory needs, or mental ill health etc).

We call on the ACT government to continue to work with all stakeholders towards **increasing the number of all residential properties (including existing and rentals) that meet accessibility standards**. As you would be aware, at the present time, only a small percentage of homes available on the private rental market, across Australia, are accessible. In our view –at any point when renovations are being considered, landlords should be encouraged and incentivised to meet housing accessibility standards, and built in sustainable ways, that reduce cost of living (e.g. future utility bills).

Improving housing accessibility facilitates better outcomes in Housing and home, Social connection and Identity and belonging domains.

3.5.3 Dynamic “housing plus” solutions for people in complex circumstances

At the present time, there continues to be people with disability, people with mental ill health and older people in unsuitable situations, such as

- living in hospital beyond when their acute health needs have been addressed (which can be a dangerous setting due to the increased risk of infectious disease especially if people are immunocompromised)
- continuing to live in dangerous settings/scenarios (homelessness, or situations of abuse/neglect) as there are undue barriers to enough alternatives or to sufficient emergency/crisis accommodation with the right supports^{xxiii}
- detained at the Alexander Maconochie Centre at times longer than the absolute minimum detention period, related to difficulties in obtaining suitable housing
- Impacts in family restoration processes (in situations where children are being restored to their family), which are dependent on appropriate housing arrangements

We urge the ACT government to continue to work with people with lived experience, services and the broader community towards faster housing access, and other supports as needed.

3.6 Family support and Child Protection

The focus of the child protection systems must shift toward **early and intensive support for families, young people and children, in ways that suit what each person/family needs**. We envisage that there will be economic savings, as well as improved outcomes for the families concerned if early support (in ways that suit for each family) were to be provided. We highlight especially the need to ensure early supports can meet the needs of all parents in their full diversity (including parents and families where there are family members with disability).

We urge the government to continue towards **full implementation of the recommendations of the *Our Boori's Our Way report***, as well as the other reviews that have occurred over the last few years, all of which highlight the need for radical transformation in the child and family space.

For parents with disability or mental ill health, early support must additionally include independent advocacy throughout the entire child protection process and legal support for all legal aspects, to mitigate the risk of unjust outcomes, and to ensure equitable experiences (as per the goals outlined in the ACT Government's Disability Justice Strategy).

Providing support early, in ways tailored to the needs of each individual/family, to seek to ensure that when possible, families can stay together, would have immeasurably positive impacts on the wellbeing of the children, young people and families concerned.

ADACAS has undertaken a project that confirms that parents with disability require early supports and at times support that is episodic to assist them at specific times. We urge the government to work with the community sector to develop initiatives that bring all the required supports to the attention of parents with disability and have a navigation advocacy service to facilitate and support them to access the supports they need when they need them.

3.7 Addressing violence, abuse, neglect and exploitation.

Given the ACT government's focus on wellbeing of all people in the ACT and the significant investment made to undertake a diverse range of community engagements to understand and address critical issues that impact citizens we seek commitment and support to fully implement :

- the *Royal Commission into Aged Care Quality and Safety* recommendations and findings,
- the *Productivity Commission into Mental Health* finding, and in relation to
- the *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* interim report and upcoming final report.
- *National plan to reduce violence against Women and Children 2022-2032*

In addition to ADACAS additionally encourages expansion of the Official Visitors Scheme, to include Aged Care Official visitors.

ADACAS also urges the ACT government to commit to fund critical sexual assault prevention and reform measures that were contained in the *Listen. Take Action to Prevent, Heal and Believe report*, which arose from a broad group of lived experience and other stakeholders across the ACT.

Violence, abuse, neglect, exploitation, also sexual assault have profoundly negative (sometimes) lifetime impacts in terms of wellbeing domains of health, safety, living and social connection for both people directly affected, and those around the people that are. There can be ripple effects in terms of finances, ability to work, living standards and onwards. It is vital that as a society we work together to better prevent, support and respond in relation to these topics, and uphold the human rights of victim/survivors.

3.8 Cost of Living

We highlight the ongoing need to address **cost of living pressures**, especially for people in difficult financial circumstances. Whilst we appreciate that some of the levers in this space (for example in relation to Centrelink) sit with the Commonwealth government, we encourage continued advocacy around “**raising the rate**” of the **Jobseeker and related allowances above the poverty line**, and in improving Centrelink structures/systems so that people who need the Disability Support Pension, or the Aged Care Pension can more easily access it.

At present, there continues to be many people with disability/mental ill health who are receiving JobSeeker rather than the Disability Support Pension^{xxiv} – which, given that having disability and/or mental ill health often results in additional costs^{xxv} – can mean that they are even further disadvantaged than others. It is important to recognise that only approximately 10% of people with disability are currently able to access the NDIS, and most people over the age of 65 are not eligible under current eligibility criteria.

We encourage also strong consideration of other ACT based initiatives to address cost of living pressures especially for those living in poverty. **Poverty profoundly and negatively affects wellbeing** – contributing negatively to multiple different domains of the ACT wellbeing framework, including but not limited to:

- Impacts of living in insecure, unsafe and/or poor-quality **housing**, also homelessness
- impacts on **health**: people being unable to afford healthcare and medications, food, or heating during cold Canberra winters.
- Negatively impacting **social connection**) or on **education** and employment opportunities
- Affecting **living standards** and **safety**.

We urge the ACT government to work together with the Federal government, community services and the community more generally, to address cost of living pressures especially for those living in poverty, given the potential to impact positively multiple domains of wellbeing for many people simultaneously.

4 Conclusion

In ADACAS' view, it is important that the ACT government's longer term expenditure and revenue priorities focus strongly on ensuring **human rights are upheld**, and that **equitable outcomes proportionate to need are achieved** for the people of Canberra and surrounds.

As we have highlighted in this submission – we strongly recommend prioritising improving wellbeing in relation to the following themes:

- Individual Advocacy
- Supported Decision Making
- Disability Strategy
- Access to and experiences of Justice
- First Nations people
- Housing and homelessness
- Increasing Family support and child protection
- Addressing violence, abuse, neglect and exploitation
- Cost of living.

With all the reforms which have emerged and continue to from the Aged Care and Disability Royal Commissions, Productivity Commission Mental Health, Australia's Disability Strategy, and reforms emerging from the Commissioning Approach, it is important to **ensure that reforms work in a cohesive way** and provide better wellbeing outcomes.

As the ACT celebrates 20 years as a human rights jurisdiction, and that the ACT government and community are seeking to operate in a Wellbeing framework - we have an especial responsibility to **address entrenched disadvantage** and to **ensure that the needs of those in the most difficult of circumstances are being adequately prioritised** and responded to.

Please do not hesitate to contact ADACAS if you would like to discuss any aspect of this submission further.

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