Carers Tasmania's Submission to the Inquiry into the Health Impacts of Alcohol and Other Drugs in Australia

September 2024

About Carers Tasmania

Carers Tasmania is the Peak Body representing the more than 87,000 informal carers (hereafter carers) in the state.

Carers Tasmania's vision is for an Australia that values and supports carers.

Our mission is to work to improve the health, wellbeing, resilience and financial security of carers and to ensure that caring is a shared responsibility of family, community, and government.

Our values drive everything we think, say, and do.

- **Carers first** – we listen to what carers need, commit to their desired action plan, and deliver results that matter most to carers
- **Care in all we do** – we care for our work, about each other, about Tasmania's family and friend carers, and the bigger world we all share
- **Integrity always** – we are transparent, act ethically, own when things don't go to plan and do what we say we will
- **Quality every time** – we don't accept 'good enough' because carers deserve our very best every time
- **Speed that matters** – we are agile and don't put off what can be done today.

These values represent how we engage with and serve carers, how we work with each other, and our commitment to the broader community. Carers Tasmania encourages partnership with governments and health and community sectors to enhance service provision and improve conditions for family or friend carers through policy development, research and advocacy.

We acknowledge and support people of all genders, sexualities, cultural beliefs, and abilities and understand that carers in Tasmania, whilst sharing the common theme of caring for a family member or friend, are diverse individuals with varying beliefs, experiences, and identities. We value and respect the diversity of carers, their lived and living experiences, and recognise that carers are the experts in their own lives.

Carers Tasmania has offices in Moonah, Launceston and Burnie.

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1. Background

Carers Tasmania is the Peak Body representing the more than 87,000 informal carers within the state.

A carer is a person who provides unpaid care and support to a family member, or friend, with disability, mental ill health, a chronic or life-limiting condition, alcohol or other drug dependence, or who is frail or aged. Informal kinship carers who care for a child under the age of 18, because the parent is unable to, are also recognised as carers. Carers are predominantly family members, but may also be friends, neighbours, or colleagues. Informal carers are not to be confused with paid support workers who are often called 'carers', with the difference being that support workers are fully employed and remunerated with all the benefits of employment. On the contrary, informal carers perform their caring duties without remuneration, other than minimal carer payments and allowances from the Australian Government.

In addition to representing carers through the Peak Body activities, Carers Tasmania provides support to carers living in Tasmania through its service delivery arm, Care2Serve. The Australian Government Carer Gateway program is delivered through Care2Serve in Tasmania, as are other supports and services, such as the Tasmanian Government's Home and Community Care program.

The Carer Gateway program provides a range of services and supports for carers which are designed to build resilience, increase wellbeing, improve quality of life, and sustain carers to effectively continue their caring roles. The available supports include the provision of information, advice and referrals, holistic identification of carer strengths and needs through a carer support planning process, professional counselling, peer support, and coaching which aims to support carers in achieving specific goals.

Care2Serve, through the Carer Gateway, has capacity to fund certain instances of planned, practical support services such as in-home respite, personal care, domestic assistance, and meal preparation. Care2Serve may also fund items such as laptops to assist carers who are studying or trying to enter the workforce. Care2Serve also coordinates the provision of emergency support during instances where a carer may be unable to provide the care that they usually do, resulting from unexpected illness or injury of the carer.

2. Introduction

Carers Tasmania thanks the Australian Government's Standing Committee on Health, Aged Care and Sport for the opportunity to provide a submission to the Inquiry into the Health Impacts of Alcohol and Other Drugs in Australia. Our response provides some insight into the health, social, and other impacts of caring for a family member or friend who has alcohol or other drug dependence.

Carers Tasmania supports the Alcohol, Tobacco and other Drugs Council of Tasmania's Communications Charter, and highlights the shared view that "*alcohol, tobacco and other drug use is a complex health issue with many contributing factors"* and that we must recognise that *"people are at the heart of alcohol, tobacco and other drug use."* [1] For these reasons, we advocate for alcohol and other drug dependence to be seen as a health issue, for sustainable funding to allow equitable support, for ongoing education and stigma reduction, and for policies and processes within the alcohol and other drug space to ensure that carers are recognised, included and supported, to help them access the support they require for themselves and the people they care for.

Carers Tasmania refers to the Tasmanian *Carer Recognition Act 2023*, which defines a carer as:

> *"A person who provides unpaid care and support to a family member, or friend, who:*
>
> *(a) has disability,*
>
> *(b) has mental ill health,*
>
> *(c) has a chronic or life-limiting condition,*
>
> *(d) has alcohol or other drug dependence,*
>
> *(e) is frail or aged, or*
>
> *(f) is a child, if the person is an informal kinship carer of the child."* [2]

Although not explicitly stated, this definition is inclusive of young carers. In Tasmania, there are an estimated 9,300 young people aged 25 or under who are supporting someone who needs additional help. This may include supporting someone with an alcohol or other drug dependence.

Our submission does not directly answer each inquiry question. However, our response addresses many of the items listed within the terms of reference (ToR), as highlighted below:

a) *"Assess whether current services across the alcohol and other drugs sector is delivering equity for all Australians, value for money, and the best outcomes for individuals, their families, and society,*

b) *Examine the effectiveness of current programs and initiatives across all jurisdictions to improve prevention and reduction of alcohol and other drug-related health, social and economic harms, including in relation to identified priority populations and ensuring equity of access for all Australians to relevant treatment and prevention services,*

[1] Alcohol, Tobacco, Other Dugs Council Tasmania. (n.d). Communications Charter. Tasmanian-ATOD-Communications-Charter.pdf (atdc.org.au)
[2] Tasmanian Government. (2023). Tasmanian Carer Recognition Act (2023). Retrieved from: lh (legislation.tas.gov.au)

c) *Examine how sectors beyond health, including for example education, employment, justice, social services and housing can contribute to prevention, early intervention, recovery and reduction of alcohol and other drug-related harms in Australia, and*

d) *Draw on domestic and international policy experiences and best practice, where appropriate."* [3]

A major aim of this response is to ensure that carers of people with alcohol or other drug dependence are recognised, considered, and included in any future policy or program reform. Throughout this response, for simplicity, carers of people with alcohol or other drug dependence are referred to as AOD carers, as to not confuse this group with carers more broadly.

Within this response, Carers Tasmania highlights:

- The need for consistent recognition of AOD carers
- Experiences of AOD carers in Tasmania
- The need to recognise, consider and include AOD carers in policy, services and supports.

Carers Tasmania thanks and acknowledges the lived experience expertise and feedback shared by Tasmanian carers to inform this submission.

3. Consistent recognition of AOD carers is required

Research estimates that one in three Australians have been impacted in some way by the use of alcohol or other drugs (AOD) by a person close to them.[4] Often, the people who are most affected by another person's alcohol or other drug use are family and friend carers. Although not all people who use alcohol or other drugs will develop a dependence, or encounter issues from the substance use, many do. Often, AOD use and dependence have far reaching impacts beyond the individual. It is important that there are clear pathways for AOD carers to access support for themselves, as their caring responsibilities and experiences can impact their own physical, mental, and emotional health.

Without consistent definitions of who carers are, it is increasingly difficult for carers of people with alcohol or other drug dependence to access supports.

Across various pieces of carer recognition legislation within Australia, there are discrepancies in who is considered a carer. Tasmania was the last state to pass carer recognition legislation, with the *Tasmanian Carer Recognition Act 2023*, enacted in April 2023.[5] The definition of a carer in this legislation is person-centred, inclusive and aims to reduce stigma to ensure that as many carers as possible can access support. Tasmania is the only state to formally recognise through legislation, carers of people who have an alcohol or other drug dependence. This cohort of carers is not formally recognised in the

[3] Inquiry into the health impacts of alcohol and other drugs in Australia – Parliament of Australia (aph.gov.au)
[4] Room R, Ferris J, Laslett AM, Livingston M, Mugavin J, Wilkinson C. The drinker's effect on the social environment Int J Environ Res Public Health. 2010;7(4):1855 1871. doi:10.3390/ijerph7041855
[5] Tasmanian Government. (2023). Tasmanian Carer Recognition Act (2023). Retrieved from: lh (legislation.tas.gov.au)

Commonwealth Carer Recognition Act 2010,[6] or within other state and territory pieces of legislation.

This creates challenges and reinforces the lack of responsibility for government funded services across Australia to truly recognise and support carers within AOD services. Within the *Tasmanian Carer Recognition Act* sits a Carers Charter. This Charter outlines the ways in which carers should expect to be treated and included across Tasmanian Government services. This includes for carers supporting a person with AOD dependence. Aspects of the Charter echo the literature within frameworks such as the Triangle method of care,[7] family centred planning[8] and the United Nations Declaration of Human Rights.[9]

The Tasmanian Carer Charter States:

> *"1. Carers should be acknowledged as diverse and are to be treated as individuals with their own needs within, and beyond, their roles as carers.*
>
> *2. Carers should be consulted in relation to the development and evaluation of policies and programs, and the provision of resources, in so far as those policies, programs and resources affect their role as carers.*
>
> *3. Carers should be empowered to access information and services that are relevant to them in their role as carers.*
>
> *4. Carers should be supported to participate in, and contribute to, the social, political, economic and cultural life of Tasmania, if they so desire.*
>
> *5. Carers should be recognised and respected for their valuable caring role and should be supported in accessing, and engaging in, a wide range of services to ensure their well-being and to maintain their connections to their community.*
>
> *6. Carers' knowledge about the persons for whom they are caring should be respected, acknowledging that each carer, and each person being cared for, has both rights and responsibilities.*
>
> *7. Carers should be able to raise concerns about decisions, and services, that affect them as carers or the persons for whom they are caring, without the carers or such persons suffering adverse repercussions, and those concerns should be dealt with as promptly as is reasonably practicable."* [10]

The Carer Recognition Act and the Carer Charter are both still relatively new, and require much work and education to implement, but small steps are being taken. One such example is the level of reference to carers and carer inclusion within the recently released *Tasmanian Drug Strategy.*[11]

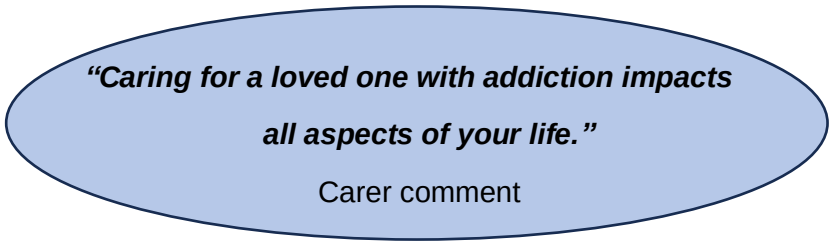
[6] Australian Government. (2010). Commonwealth Carer Recognition Act. Federal Register of Legislation - Carer Recognition Act 2010
[7] Carers Trust. (2024). The Triangle of Care. The Triangle of Care (carers.org)
[8] Towards a universal model of family centered care: a scoping review | BMC Health Services Research | Full Text (biomedcentral.com)
[9] Universal Declaration of Human Rights | United Nations
[10] Tasmanian Government. (2023). Tasmanian Carer Recognition Act (2023). Retrieved from: lh (legislation.tas.gov.au)
[11] Tasmanian Government Department of Health. (2024). Tasmanian Drug Strategy 2024-2029 | Tasmanian Department of Health

Stigma about the use of alcohol or other drugs is a significant issue, not only for the people who use alcohol or other drugs, but also their carers. On a global level, The World Health Organisation ranked dependence on illicit drugs as the most stigmatised health condition, and alcohol dependence as the fourth most stigmatised health condition.[12] Stigma not only impacts the person using alcohol or other drugs, but also the carers of people who have alcohol or other drug dependence. The Alcohol and Drug Foundation (ADF) suggests that there are many negative impacts of stigma on people with alcohol or other drug dependence and their carers, such as social isolation, poor self-worth, fear, stress, strained relationships, and lack of access to supports.[13] Furthermore, the ADF describes three main types of problems that contribute to stigma, which include knowledge, attitudes, and behaviour.[14]

By recognising AOD carers and ensuring they are included and supported by policy, programs, and services, the knowledge, attitudes and behaviours around alcohol and other drug dependence, particularly for carers, may change. If carers are better supported, they have a better chance of sustaining their caring role and supporting the person they care for to access appropriate and safe support. This in turn, will help reduce negative impacts on carers, therefore supporting the family or friend unit collaboratively.

Addressing the stigma associated with alcohol and other drug dependence requires a multi-systemic approach that involves adequate education, training and reform across various legislative frameworks, governments, policies, institutions and services, and at individual levels.

4. Experiences from AOD carers in Tasmania



Research has found that carers who support someone who has a drug or alcohol dependence report higher levels of psychological distress and lower satisfaction with their personal health when compared with other groups of carers.[15]

Tasmania ranks poorly against many health measures when compared with other Australian states and territories.[16] For example, the 2021 Census found that rates of health conditions such as asthma, cancer, dementia, heart diseases, stroke, mental ill health, lung conditions, diabetes and kidney disease were higher in Tasmania in comparison to Australia as a whole.[17] Reports such as *the Primary Health Tasmania Needs Assessments*, indicate that

[12] Kelly JF, Westerhoff CM. Does it matter how we refer to individuals with substance-related conditions? A randomized study of two commonly used terms. International Journal of Drug Policy. 2010 May 1;21(3):202–7
[13] Alcohol and Drug Foundation. (2019). Alcohol and other drugs: stigma. https://cdn.adf.org.au/media/documents/ADF_Stigma_background_paper.pdf
[14] Ibid.
[15] Carers NSW (2018). Carers NSW 2018 Carer Survey: Summary report. Available online at: http://www.carersnsw.org.au/research/survey
[16] Primary Health Tasmania. (2022). Health Needs Assessment. https://www.primaryhealthtas.com.au/wp-content/uploads/2023/05/Health-in-Tasmania-Comprehensive-Needs-Assessment-2022-25.pdf
[17] Australian Bureau of Statistics. (2022). Tasmania 2021 Census All Person QuickStats. https://www.abs.gov.au/census/find-census-data/quickstats/2021/6

rates of alcohol consumption are higher in Tasmania in comparison to Australia overall, and similar rates of illicit drug use in Tasmania to the rest of Australia.[18]

Given these statistics, Carers Tasmania developed a short, online survey to capture some experiences about the impacts of alcohol and other drug use from AOD carers in Tasmania to add to what we already know from many years of working within this space. These results are important and will contribute to the ongoing advocacy of Carers Tasmania. The survey is currently unpublished and remains open to assist in further data collection. The following sections include thoughts, ideas and experiences of AOD carers, gathered through the survey. Although these results are not statistically representative of all AOD carers, they do provide insights from a small number of AOD carers currently living in Tasmania.

Does the person you care for have any other co-occurring conditions?

It is common for people with alcohol or other drug dependence to also have co-occurring conditions. The survey asked carers to report what other conditions in addition to alcohol and other drug dependence they were supporting someone with. Some of these conditions are listed below:

- *Diabetes*
- *Mental Illness, bi-polar, anxiety, attention deficit disorder, cancer recovery patient*
- *PTSD*
- *Schizophrenia*
- *ADHD, depression and anxiety*
- *Alzheimer's and type 2 diabetes, cardiac stents*
- *ABI, osteoarthritis, injuries and pain, lumbar back disease*
- *Previous ankle injury now causing chronic pain and increasing inability to work and walk longer distances*
- *Foetal alcohol spectrum disorder (FASD), developmental language disorder.*

Who can AOD carers talk to?

The survey asked AOD carers to identify who they can talk to about their caring role. The following are some responses:

- *My sister and mother*
- *My cousin who is a support to me mentally when things are very difficult*
- *Friend is a social worker*
- *Friends, GP and alcohol and drug services*
- *Counsellor*
- *Psychologist, Safe Families, ADHD specialist*
- *Psychologist, friends, family*
- *Partner*
- *Family*
- *Friends, family, Carers Tas counsellor.*

[18] Primary Health Tasmania. (2022). Health Needs Assessment. https://www.primaryhealthtas.com.au/wp-content/uploads/2023/05/Health-in-Tasmania-Comprehensive-Needs-Assessment-2022-25.pdf

What sort of support has the person you care for accessed?

The survey asked about what types of supports the person being cared for has engaged with. Some of the results included:

- *Psychological services, domestic violence support, family support. Refuses to engage with AOD services*
- *Mental health services, psychologist*
- *Psychologist*
- *None yet*
- *Own GP Specialist, consult at Drug and alcohol service, Peer support, outreach, medication*
- *None, refuses to recognise his alcoholism*
- *Some services have been accessed before but it's difficult to motivate her to go anywhere and she won't let anyone come to the house. I have finally got an appointment with the local clinic*
- *Alcohol and drug services, mental health services, GP*
- *Head to Health.*

What sort of barriers have you experienced in helping the person access support?

The survey asked carers about whether they had experienced any barriers in trying to support the person they care for to access AOD supports. Some of the responses included:

- *Transport,* cost
- *None*
- *Inflexibility*
- *Lack of skilled professionals in Tasmania waiting list is enormous*
- *My partners denial fear and anxiety are main blocks*
- *Lack of wanting help/accepting it's a problem*
- *Time frames and waiting periods. When someone is in crisis and wants the help they want it NOW - not in 4 weeks' time*
- *They won't participate, refusal to engage with AOD providers*
- *They are not interested*
- *Yes, self-caused barriers, e.g. not attending appointments*
- *She is 17, and has a developmental disability, it has taken me a year to get her in to see a paediatrician, she refuses to see anyone else*
- *Need easy access to non-religious detox and rehab for free*
- *There is a lack of skilled professionals in Tasmania, waiting list is enormous.*

Where do you find information about how to support this person?

The survey asked carers about how they find relevant information to assist them in supporting the person they care for. Some of the answers included:

- *Google*
- *Referrals from health professionals, social worker, online*
- *Website, mental health services*
- *Through information supplied*
- *Own research. Hospital contacts in the community. Special people who have cared and taken time*
- *A registered carer has access to information and support*
- *I'm a retired nurse and am familiar with alcoholism to a degree*
- *Carer gateway, school social worker*
- *Friends, drug and alcohol services, mental health services*
- *Friends, Facebook support groups.*

What sort of support have you accessed for yourself?

The survey asked carers to describe what sort of supports they have accessed for themselves to assist them in their role as an AOD carer. Some of the responses are listed below:

- *Psychologist, safe families*
- *Psychologist, medication, GP, support groups, education*
- *None*
- *Carer Gateway*
- *Salvation Army*
- *Had to seek counselling myself, reached out to alcoholics anonymous for support on living with a loved one with addiction*
- *None*
- *Minimal counselling Recently some practical garden assistance through care2serve Remain educated*
- *counselling educational courses*
- *Online info and books*
- *See a psychologist sometimes*
- *Seeing the social workers.*

How does this caring role impact you?

There are many significant, negative impacts associated with caring for a person who has alcohol or other drug dependence. The survey asked carers to identify how their caring role has impacted them. Some of the answers are presented below and categorised into relevant categories:

Socially and emotionally

- *It is really hard to watch a person you love put themselves through life with addiction and the impacts this has on them. I get abused regularly and feel like I am walking on eggshells. I hope they will change and keep encouraging them.*
- *It has been challenging mentally and emotionally. Was in denial about problem for a long time which was worse. Easier now that I have accepted reality and my role (able to love and care; but unable to change him). Still saddens me deeply and I feel angry*

generally when I see ignorance of alcohol related harms and unwillingness to challenge these unhealthy norms. I have and continue to do a lot of work to keep centred

- *It's a big strain on me and my family*
- *I'm constantly tired, physically and emotionally*
- *I'm exhausted all the time*
- *Anxiety and worry*
- *It makes me very sad, very tired, and makes me feel very low sometimes*
- *I feel sad and exhausted a lot.*
- *It can at times be wearing*
- *Burn out is common*
- *I have withdrawn socially*
- *I've reduced time with friends*
- *I have no friends.*
- *Less likely to attend functions as a couple..if alcohol present! But have good long term friends that understand..*
- *People can be judgemental and opinionated*
- *No time or capacity for anything else.*
- *I only can see friends once per month*
- *I don't have time for social connections*
- *I don't want to socialise, my friends have had enough of the drama*
- *Everyone thinks I'm an idiot for caring.*

Employment or education

- *Disrupted days at work and had to leave work early due to ongoing issues*
- *I retired early after taking leave and then reducing hours*
- *I have to use all my annual leave for supporting them so I don't really get time off*
- *I prioritise work according to my caring role*
- *Getting help had been very frustrating and way too conservative, slow and lacking.*
- *Has been very problematic in the past. We are low-income earners and alcohol expenditure has been high proportionately over the years. This has caused some hardship & resentment. In recent years I established my own separate savings and this has helped feelings of resentment a lot*
- *I can't go back to work, I'm on leave without pay.*

Financially

- *Main income earner, so only just surviving from pay week to pay week*
- *I maintain my work, but it is tiring and I feel depressed*
- *Cost of everything means I can't save very much*
- *Very costly*
- *Have held part time role around caring role*
- *No problems currently*
- *Our daughter causes us a lot of expense by damaging items in the home and by failing to budget*
- *Centrelink creating huge stress and not having any understanding of how alcoholism impacts your ability to work or look for work.*

Do you have any health concerns, physical or psychosocial disability yourself?

The survey asked carers to identify any health concerns or disability they were experiencing themselves. As of 30 October 2024, 85% of AOD carer respondents from the survey indicated they had a health concern, psychosocial or physical disability themselves. The following comments provide some additional information:

- *AuDHD (Autism and ADHD)*
- *Depression and anxiety*
- *ADHD*
- *Osteoarthritis*
- *Anxiety*
- *ADHD, depression, anxiety, Hashimoto's disease*
- *Major depressive disorder*
- *Insomnia.*

What support do you need?

An aim of the survey was to help identify areas of additional support required by carers. Some of the responses are provided below:

- *More support for my child*
- *Specific counselling for families dealing with addictions to alcohol and other drugs*
- *It wears me down, psychologist helps but I don't think there is much more that can be done*
- *Case management*
- *Practical support is beneficial. Education is good. More trauma informed workforce/drug and alcohol education for those supporting people with disabilities*
- *Respect and compassion around the grief involved in long-term caring*
- *Educational courses, counselling, support group meetings*
- *Still much to be done in this area. Train more professionals, employ more workers, more flexible options for people of all backgrounds to feel safe*
- *Resources available to carers is paramount to their caring role advocating this is a very important permanent journey*
- *More support from the actual rehabilitation staff and program experts*
- *Having a list of phone numbers for support ideas would be helpful that can attach to the fridge or somewhere accessible. It's so hard to know who to turn to when things are so up and down with relapses and all movement forward is slow and difficult*
- *It would be great if our daughter could stay for short periods in a hostel or similar.*

Carers of people with alcohol and other drug dependence often face unique challenges, stigma and barriers to accessing support compared to some other groups of carers. It is common for people with alcohol and other drug dependence to also experience co-occurring issues such as mental ill health, and chronic or life-limiting illness. For this reason, it's incredibly important that AOD carers not only have access to supports specific to their AOD caring circumstances, but they must also have access to mainstream carer supports.

Carers Tasmania highlights two specific groups of carers who may be significantly impacted by alcohol and other drug dependence. These groups are young carers and informal kinship carers. Alcohol and other drug dependence is often a contributing factor leading to family members taking up informal kinship care of children (quite often grandchildren). Without informal kinship carers, those children end up in other out-of-home care arrangements or

may continue to live in unsafe environments. Research shows that parental use of alcohol or other drugs is related to approximately 50-80% of family situations involved with child welfare systems across Australia.[19]

In Tasmania, is estimated that there are approximately 1,600 grandparents looking after children (via either formal and informal kinship arrangements),[20] and over 1,200 children are in some form of informal kinship care arrangement. However, there is not one standard source of reliable data on this, and these statistics are based on records of those who have accessed services or information regarding informal kinship care.[21]

While kinship carers might not be directly supporting a person with alcohol or other drug dependence, their life may certainly be impacted. During a consultation period in 2023, Carers Tasmania heard from many informal kinship carers who were supporting a child within their family, some due to alcohol or other drug dependence by the child's parent.[22] Informal kinship carers described experiences of stigma, shame, and judgement about their family circumstances.

For grandparent informal kinship carers, these experiences of shame, guilt, and stigma were often significant. As result of parental alcohol or other drug dependence, some of these informal kinship carers were supporting children who had experienced trauma, were living with mental ill health, chronic illness, and disability or health conditions such as foetal alcohol spectrum disorder (FASD) and behavioural challenges. A difficulty described for informal kinship carers was the lack of access to relevant information and supports, compared to those involved in formal out-of-home care scenarios.[23]

As described previously, the impacts of alcohol or other drug dependence are not only experienced by adults, but quite commonly by children and young people within families. Some of these children and young people may take on more responsibility and support for the family member, or other family members, and therefore may be young carers. A recent report found that around one in five Tasmanians who had dependent children drank more than the recommended amount of alcohol.[24]

In Tasmania, it is estimated that there are 9,300 young carers aged 25 or under.[25] It is critical that methods to identify and support young carers are strengthened through government policy and processes. Results from the *2022 National Carer Survey* identified that of the 92 young carer survey respondents, (which included 10 young carers from Tasmania), most young carers (65.1%) were caring for a parent, and 34.9% were caring for a sibling. Although not all of these young carers were necessarily supporting someone with alcohol or other drug dependence, the findings show the need to consider and support young carers, including those supporting someone with alcohol or other drug dependence.

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[19] Battams, S., & Roche, A. (2011). Child wellbeing and protection concerns and the response of the alcohol and other drug sector in Australia. *Advances in Mental Health*, *10*(1), 62-71.
[20] Tasmanian Government Department for Education, Children and Young People. (2024). Grandparents caring for grandchildren - Department for Education, Children and Young People (decyp.tas.gov.au)
[21] Tasmanian Government Department of Communities. (2021). Informal Kinship Care Review. Informal-Kinship-Care-Summary-Review-Report.pdf (education.tas.gov.au)
[22] Carers Tasmania. (2023). Executive Summary: Understanding the experiences and needs of informal kinship carers. Executive-Summary-Understanding-the-Experiences-and-Needs-of-Informal-Kinship-Carers-2023.pdf (carerstas.org)
[23] Ibid.
[24] Primary Health Tasmania. (2022). Health Needs Assessment. https://www.primaryhealthtas.com.au/wp-content/uploads/2023/05/Health-in-Tasmania-Comprehensive-Needs-Assessment-2022-25.pdf
[25] Department of Premier and Cabinet. (n,d). https://www.dpac.tas.gov.au/divisions/cpp/community-policy-andengagement/carer_policy_and_action_plan/carer-action-plan-2021-2025/what-the-data-tells-us-about-carers

Whilst there are many positive aspects of being a young carer, research shows there can be negative implications, such as difficulties in developing and maintaining social connections,[26] poor wellbeing, and reduced educational and employment outcomes.[27] Findings show that by Year Nine of school, boys who spent two or more hours per day in a caring role were the equivalent of 1.9 years behind their peers in NAPLAN reading, and girls who provided care for two or more hours per day were 1.6 years behind in NAPLAN reading. Both boys and girls in Year 9 who were caring for at least two hours per day were approximately fifteen months behind their peers in NAPLAN numeracy. Furthermore, findings have shown that young carers were less likely to have completed Year 12 or equivalent compared to their peers, and nationally, over 60% of primary carers between the ages of 15 and 25 were not studying.[28]

Young carers face lifelong impacts in terms of poorer educational and employment outcomes, reduced social interactions with other young people and trusted adults, and difficulties accessing adequate information and support. Whilst these findings aren't necessarily representative of all young carers, they do highlight additional reasons why young carers may be particularly vulnerable or isolated, especially those who are caring for a person with alcohol or other drug dependence.

Young carers who are supporting a person, especially a parent with alcohol or other drug dependence, may be hesitant to reach out for support due to stigma, bullying, or fear of involvement by child safety services. It is important that adequate information is available in a range of formats, not only for young people who have questions about alcohol or other drug use regarding themselves or their peers, but also for young carers supporting a parent or another family member with alcohol or other drug dependence. Services must be safe and approachable for young carers to access if they are needing information and support for this reason.

5. Inclusion and support for AOD carers in policy, system and services

Carers Tasmania hopes that the findings of this inquiry will help ensure there are adequate policies for AOD carers to be included in care planning discussions, and that there are clearer pathways enabled for carers to access support. Carers Tasmania also suggests further investment into education and awareness raising, not only about the health impacts of alcohol and other drug use, but also a significant focus on stigma reduction. This will not only encourage people with alcohol and other drug dependence to ask for help, but to support their carers to do so as well. These aims align with the Carers Charter within the *Tasmanian Carer Recognition Act 2023.*[29]

[26] Moore, T., Bourke-Taylor, H., Greenland, N., McDougall, S., Bromfield, L., Robinson, L, & Brown, T. (2019). Young carers and their engagement with education: 'No space in my brain to learn'. Adelaide, SA: University of South Australia. https://www.carersaustralia.com.au/wp-content/uploads/2020/10/Young-Carers-ReportFINAL_vsmall_compressed1.pdf

[27] Becker, Saul, & Sempik, Joe. (2019). Young Adult Carers: The Impact of Caring on Health and Education. Children & Society, 33(4), 377–386. https://doi.org/10.1111/chso.12310

[28] Australian Institute of Family Studies. (2017). Longitudinal Study of Australian Children 2016 Annual Statistical Report Young Carers

[29] Tasmanian Government. (2023). Tasmanian Carer Recognition Act (2023). Retrieved from: lh (legislation.tas.gov.au)

Comments from AOD carers about inclusion in services

The survey provided an opportunity for carers to comment on their experience with service inclusion. The following are some of the comments provided:

- *Not really consistent, other than perhaps asking my thoughts, but then doing whatever anyway despite this*
- *Quite rightly they are interested and bound by the client, but it is a pity that carers are usually not privy to procedural matters, e.g. being unaware that our daughter has failed to attend appointments despite setting off in our car to drive there saying that she wishes to go alone*
- *Communication with family left behind is challenging. Hard to know who to turn to once released and relapsing.*

AOD carers must have opportunities for inclusion and participation in the development, monitoring and implementation of relevant AOD policies and programs, and we request that carers with lived or living experience have opportunities to participate in AOD peer-worker models of care. The lived experience of supporting a person with alcohol or other drug dependence can provide opportunities to strengthen knowledge, safety and connection. These skills can be complementary to the work of clinicians, especially amid workforce shortages. To support expanding the AOD peer workforce, there must be equitable pathways to access carer and consumer AOD peer work training across Australia, noting that in some states there are few opportunities for this type of formal, accredited training and development. In addition, sustainable funding and support of this approach is required from a policy perspective.

Across Australia, various forms of individual advocacy services are available. Many of these are funded to support people who are being cared for, such as those with disability, mental ill health, or those who are ageing. There is very limited individual advocacy support available for carers of people with alcohol or other drug dependence. This can lead to poor outcomes, disempowerment, lack of engagement, and can exacerbate the levels of disadvantage faced by AOD carers. As there are legal implications surrounding the use of illicit drugs, it is imperative that there is support available, not only for people with alcohol or other drug dependence, but also for their carers. As illicit drug use is seen by many only as a justice issue, and not a health issue, supporting a person in this situation can be challenging, daunting, and isolating.

Governments must ensure that adequate funding and programs are available, not only for those using alcohol or other drugs, but also for their carers. It is important for these carers to access supports specific to their AOD caring circumstances; however, it is also important for AOD carer programs to not be completely siloed from broader carer supports. As previously highlighted, there are some needs and challenges faced by AOD carers that are specific to their cohort, but many AOD carers are also supporting the person with a co-occurring condition or may be supporting another person who has a different condition.

6. Conclusion

Carers Tasmania thanks the Australian Government for the opportunity to provide feedback through this Inquiry. We acknowledge and thank the Tasmanian carers who shared their valuable experiences to help inform this response. We look forward to observing continued reforms across the alcohol and drug sector, with the hope that individuals who have alcohol and other drug dependence, and their carers, will have improved access to supports.

As previously highlighted, Carers Tasmania hopes that this Inquiry will encourage the need for alcohol and other drug dependence to be seen as a health issue, for sustainable funding to allow equitable support, and for ongoing education and stigma reduction. Furthermore, policies and processes within the alcohol and other drug space must ensure that carers are recognised, included and supported, to help them access the support they require for themselves and the people they care for.