

Victorian Voices on Alcohol Harm

December 2023



About the Victorian Voices on Alcohol Harm Network

The Victorian Voices on Alcohol Harm Network (Network) was established in 2022 with support from Foundation for Alcohol Research and Education (FARE) and the Victorian Health Promotion Foundation (VicHealth). The Network is a diverse and passionate group of Advocates in Victoria, with lived and living experiences of alcohol harm. The Network advocates for policy change and increased awareness of the factors that affect the type and extent of alcohol harm experienced in our communities.

About FARE

The Foundation for Alcohol Research and Education (FARE) is the leading not-for-profit organisation working towards an Australia free from alcohol harms. We approach this through developing evidence-informed policy, enabling people-powered advocacy and delivering health promotion programs.

Working with local communities, values-aligned organisations, health professionals and researchers across the country, we strive to improve the health and wellbeing of everyone in Australia.

About VicHealth

The Victorian Health Promotion Foundation (VicHealth) is a pioneer in health promotion – the process of enabling people to increase control over and improve their health. Our primary focus is promoting good health and preventing chronic disease.



Acknowledgment

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This report contains sensitive content

This report discusses topics that may be distressing or triggering for some individuals. The content covers themes related to mental ill health, alcohol dependence, sexual assault, violence and family violence. These subjects can evoke strong emotions and may be confronting for those who have lived experiences or sensitivities associated with these issues.

If you or someone you know is experiencing challenges with any of the topics mentioned in this report, we encourage you to contact health professionals, helplines, or support services in your area.

For information about available support, please see the FARE website at <https://fare.org.au/resources/support/>.

Key terms

Agency is the ability to take action or to choose what action to take.¹

Co-design involves working alongside people, in creating interventions, services and programs which will work in the context of their lives and will reflect their own values and goals.²

Co-production is a way of working where citizens and decision-makers, or people who use services, significant others, and service providers, work together to create a decision or service which works for them all. The approach is value driven and built on the principle that those who use a service are best placed to help design it.³

Engagement refers to the various ways that people with lived experience choose to work with organisations and institutions. For example, consultation, co-design, or appointment to working groups and committees.

Harm refers to the range of harms that alcohol causes or influences, including injuries, accidents, violence, family violence, sexual assaults, harms to children, physical and mental health conditions, and deaths.

Lived/living experience is the subjective understanding of one's experiences and decisions in life. In the context of alcohol, many people have lived or living experience of alcohol-related harms, including personal experience and/or support of a loved one.

Lived expertise is the knowledge and skills acquired through lived experience of alcohol harm.

Lived Experience Advocate is an individual with lived experience of alcohol harm, who is engaging with an organisation to share their lived experience or lived expertise.

Executive Summary

Everyone in the Victorian community should be supported to be safe and well. However, alcohol fuels significant harm to individuals, families and communities in Victoria. To ensure policies and systems are effective to keep people safe from alcohol harm and support the needs of those most affected, the voices of people with lived and living experience of alcohol harm must be elevated and heard in public conversations and policy making about alcohol in Victoria.

This report aims to showcase lived and living experiences of alcohol harm in the Victorian community. The Victorian Voices on Alcohol Harm Network (Network), a network of Advocates in Victoria with lived and living experiences of alcohol harm (Lived Experience Advocates) were engaged as active participants in co-producing research on their experiences. The research examined the Advocates' experiences of alcohol harm and other impacts, the intersections of these experiences with other issues, and their perspectives on policy implications and responses.

The Lived Experience Advocates experienced a range of alcohol harms, including alcohol use disorders or dependence, serious harms to physical and mental health, and experiences of abuse and violence. Advocates also had lived experience of Fetal Alcohol Spectrum Disorder (FASD). The Advocates' experiences included direct harms from using alcohol, harms to family members and loved ones, and experiences of caring for people harmed or affected by alcohol. The harms intersected with, and were influenced by, a range of individual, social, cultural, environmental, policy and system factors, such as health, inequality, gender and gender identity, the health and justice systems, alcohol marketing and availability, and cultural norms and pressures in relation to alcohol.

The experiences and insights of the Lived Experience Advocates centred on five key themes:

1. Mental health

Many of the Advocates described using alcohol as a coping mechanism or self-medication for mental ill-health or trauma, and of alcohol triggering or exacerbating mental health challenges. For several of the Advocates, this interconnected relationship between alcohol use and mental ill-health contributed to them developing alcohol use disorders or dependence. Some Advocates also described mental health impacts from caring for a person experiencing alcohol dependence or harm.

2. Family violence

One Advocate provided an account of family violence perpetrated to a family member by a person who used alcohol at high-risk levels and described the serious long-term consequences of the violence. The Advocate discussed the role of alcohol as a trigger and exacerbating factor in family violence, and the need for controls on alcohol delivery and trading hours to reduce these risks.

3. FASD

Two Advocates, with lived and living experiences of FASD, described the importance of, and barriers to, FASD diagnosis, with one Advocate outlining her experiences of serious long-term impacts from undiagnosed FASD. The Advocates highlighted the need for, and challenges in accessing, multidisciplinary support for people with FASD and their carers and families. The Advocates called for increased awareness, and clear, non-stigmatising guidance and support in relation to alcohol and pregnancy, and FASD.

4. Culture

All the Advocates described the pervasive cultural norms and attitudes encouraging alcohol use in Australia, and the influences of this on high-risk alcohol use and harm. Advocates highlighted the strong social pressures on young people to use alcohol, and the role of alcohol marketing, and alcohol supply and availability, in creating and reinforcing cultures of alcohol use.

5. Embedding lived experience in policy development

The Advocates emphasised the need for lived experience to inform alcohol law and policy development and other policy areas that influence alcohol use and harm. This should occur through the creation of platforms and mechanisms that facilitate meaningful engagement of Lived Experience Advocates in policy development, program and service design and implementation, through ongoing co-design and co-production processes.

Recommendations

The report makes five key recommendations for the Victorian Government to integrate lived experience into policy- and decision-making on alcohol and intersecting issues:

1. Work with Lived Experienced Advocates to co-design and publish an Alcohol Lived Experience Strategy.
2. Establish a Victorian alcohol lived experience advisory group, comprising Lived Experience Advocates from diverse communities, to advise on Government actions to reduce alcohol harm.
3. Collaborate with the alcohol lived experience advisory group to co-design and co-produce a framework for engaging Lived Experience Advocates. This should set out the vision, objectives, principles and values for the engagement, and outline solutions to overcome potential barriers to participation.
4. Engage Lived Experience Advocates in the co-design of a range of policy and program measures to reduce alcohol harm in the Victorian community, including policies to address alcohol marketing, availability, and online sales and delivery, and programs to increase awareness of alcohol harms and impacts.
5. Invest in a program of research on lived experience of alcohol harm in Victorian communities to inform laws, policy, programs and support services.

Introduction

Everyone in the Victorian community should be supported to be safe, healthy, and free from harm. However, many Victorians have experienced harm from alcohol. These harms are far reaching. They include physical and mental ill health, alcohol dependence, family violence and accident and injury. Prenatal alcohol exposure can also result in Fetal Alcohol Spectrum Disorder (FASD).

Each year, alcohol use causes the deaths of more than 4,500 Australians, including more than 1,000 Victorians. It also causes more than 80,000 Australians, including 20,000 Victorians, to be hospitalised.⁴ Global prevalence of FASD is estimated to be 7.7 per 1,000 population,⁵ although higher rates are known to exist in specific populations⁶. In addition to these direct harms from alcohol, research indicates that almost half of all Australians (around 10 million people) have been harmed from another person's alcohol use.⁷

Data shows that alcohol fuelled harms in Victoria and Australia are increasing. The rate of alcohol-induced deaths in Australia in 2021 was the highest it has been for 10 years,⁸ and deaths from alcohol-related injuries have more than doubled over the past decade.⁹ During the same period in Victoria, the rate and number of hospital admissions and ambulance attendances for alcohol harm rose dramatically.¹⁰

A focus on data alone can obscure the real-life pain, suffering and trauma experienced by people harmed by alcohol, as well as the far-reaching ripple effects on the health and wellbeing of their families and loved ones.

Reducing alcohol harm in Victoria requires meaningful and sustained engagement with the people and communities who are most affected by alcohol products, laws, and policies. People with lived and living experience of alcohol harm are best placed to inform how laws, policies, programs and systems can be designed and implemented to best meet their needs. Their voices should be elevated and listened to in public conversations about alcohol harm, and decision-making on policy responses.

Engaging people with lived and living experience as active partners in co-design and co-production ensures policies are informed by those who are most affected. This provides a range of benefits for people and communities, as well as the people themselves, and increases the likelihood that policies are effective to address the needs of the people most harmed.

About this report

This report provides an overview of the Victorian Voices on Alcohol Harm Network, a network of people in Victoria with lived and living experiences of alcohol harm (Lived Experience Advocates) who share their perspectives to influence public conversations, policy making and decisions.

The report presents peer-led qualitative research that captures Lived Experience Advocates' unique and diverse experiences of alcohol harm in Victoria. Supported by relevant quantitative research and data, this qualitative evidence makes a valuable contribution to the body of evidence on alcohol harm in Victoria.

The report aims to demonstrate the following:

- The extent of alcohol harm that people experience in the Victorian community.
- How alcohol harm intersects with other issues of social injustice or inequality, enabling identification of policy areas that play a role in contributing, or responding, to alcohol harm.
- The importance of including lived experience in policy development.

By providing Lived Experience Advocates with a mechanism to tell their stories of alcohol harm in their own words, and to co-produce qualitative research to build the narrative and evidence base on alcohol harm in Victoria, the report aims to help empower and build the skills and capacity of the Advocates to be the producers of valuable knowledge and evidence, and effective advocates for policy change.

Benefits of research for people and communities

The expertise and real-world perspectives of Lived Experience Advocates are critical in improving and disseminating knowledge and building the evidence base on alcohol harm in Victoria. Integration of lived experience of alcohol harm improves the quality, relevance and knowledge translation of alcohol research.

Lived Experience Advocates are best placed to inform and co-design policies, programs, implementation and evaluation on alcohol and intersecting issues. Their real-world insights are essential to help policy makers better understand how people experience diverse alcohol harms, and other factors that influence, drive or intersect with these harms, helping to build a deeper, more nuanced and multidimensional understanding.

The lived expertise of Advocates is also critical in informing and designing policies that are effective and tailored to address different types of alcohol harm, and that meet the diverse needs of the people and communities most affected. This includes not just specific alcohol policies, but also the broad range of policies and programs that influence the level and type of alcohol harm experienced in our communities.

Elevating the voices of Lived Experience Advocates raises community awareness and deepens understanding of the risks from alcohol and can help to reduce stigma. It strengthens advocacy for policy change, by encouraging empathy and understanding in the community, and by boosting credibility with decision makers, increasing the likelihood that effective policies will be adopted.

Benefits of research for Lived Experience Advocates

The inclusion of Lived Experience Advocates as active partners in co-design and co-production of research and policy builds Advocates' capacity, providing them with opportunities to use and practise existing skills, and to develop and strengthen skills in research, knowledge production, policy design and advocacy. It enables Advocates to contribute to changes that are meaningful to them, see tangible outcomes that benefit people and communities, and feel that their voices are elevated and heard in public discussions and decision making. This creates important opportunities for leadership, connection and networking, and for their work and contributions to be valued through payment, reimbursement or recognition, such as through public consultations, advisory boards or employment.

Progress in embedding lived experience in policy making in Victoria and Australia

The importance of elevating and listening to the voices of people with lived experience, and engaging them in co-design of policies and programs that affect them, is gaining growing recognition and momentum across a range of social issues. Increasingly, governments in Australia are including the expertise and unique perspectives of people with lived experience in policy making and workforces. Nationally, most progress has occurred in mental health. For example, the National Mental Health Commission led the development of *National Lived Experience Workforce Development Guidelines* to create a framework for consistent national development of the Lived Experience workforce in mental health, through a process of consultation and co-production.¹¹ In January 2023, the Australian Government announced that it would invest \$8.5 million to support those with a lived experience of mental ill-health to shape the policies and programs that affect them.¹²

The Victorian Government has also been a leader in including lived experience perspectives in family violence and mental health reform. Following the 2016 Victorian Royal Commission into Family Violence, the Victorian Government established the Victim Survivors' Advisory Council to place people with diverse lived experiences of family violence at the centre of the Government's family violence reform program, and to partner with them in designing family violence reform initiatives and services.¹³

In 2022, Family Safety Victoria published the Family Violence Lived Experience Strategy, *More Than Our Story: Action, Wisdom, and Change*. This strategy was developed in partnership with the Victim Survivor's Advisory Council, with the aim of engaging people with lived experience in the design of family violence and sexual assault policy, service design and law reform.¹⁴

The Victorian Government is engaging with people with lived experience of mental ill-health, and their carers, families and supporters, to inform the design and implementation of reform initiatives recommended by the 2021 Final Report of the Royal Commission into Victoria's Mental Health System.¹⁵

In response to the Commission's recommendations, the Government has established the *Lived and Living Experience Workforce Development Program*, which aims to build a lived experience workforce that meets the needs of Victorians living with mental illness, and that co-designs a rebuilt mental health system.¹⁶ The Government has also established a new agency led by people with lived experience of mental illness or psychological distress that supports organisations to work with and employ Victorians with lived experience, including by providing accredited training and resources.¹⁷

In 2019, the Victorian Government commissioned the Lived Experience Leadership Expert Reference Group and the Victorian Mental Illness Awareness Council to co-produce the Mental Health Lived Experience Engagement Framework with consumers of mental health services and their carers. The Framework provides guidance for

actively partnering with people who use mental health services to ensure services are improved to meet their needs.¹⁸

There is significant need and opportunity for the Victorian Government to elevate the voices of Victorians with diverse lived experiences of alcohol harm, and ensure they are embedded in policy making and program design in Victoria.

The Approach

The following steps were taken to co-design and co-produce the research for this report:

1. Seven Lived Experience Advocates in the Network were active participants and co-producers in the research.
2. Through a series of Network meetings, Lived Experience Advocates and FARE worked together closely to generate and refine ideas for the research, and to co-design the research aims, scope and methodology, and the structure and themes of the report.
3. FARE conducted in-depth semi-structured 90-minute interviews of the seven Lived Experience Advocates between 17 April 2023 and 15 May 2023. The interviews provided opportunities for the Advocates to describe in their own words their experiences of alcohol harm, how their experiences intersected with or were influenced by other issues, and their views and insights on policy implications. With the permission of the Advocates, the interviews were recorded and transcribed. Prior to the interviews, FARE shared the interview questions with Advocates, who provided their informed consent to participate.
4. Lead researchers analysed the interview transcripts to identify themes, develop case studies of each Advocate's experiences, and to analyse and interpret the alcohol harms they experienced, and intersecting social and policy issues they identified.
5. Lead researchers identified literature and quantitative research relevant to these harms, issues and themes.
6. Relevant Victorian and Australian policies on alcohol and other issues, and links between these policies and Advocates' experiences of alcohol harm, were also identified.
7. A series of policy recommendations for including lived experience in Victorian and Australian policy making were developed by researchers in consultation with Lived Experience Advocates.
8. FARE and researchers worked in close partnership with the Lived Experience Advocates throughout the project, including to generate research ideas, develop the report aims, scope, structure and themes, analyse and interpret Advocates' experiences to identify intersecting issues, themes and policy implications; and to seek and incorporate feedback on Advocates' stories, research findings, policy recommendations and report drafts.

Throughout the project, FARE took steps to protect and promote the health and wellbeing of Lived Experience Advocates, including by providing a working environment as free as possible from physical and psychological health risks, ensuring Lived Experience Advocates were adequately trained and prepared to participate in the project, promoting health and wellbeing throughout the project, including through regular check-ins and debriefings, providing a staff member with training in trauma-informed facilitation to facilitate the group, and understanding and monitoring the potential impacts for Lived Experience Advocates of participating in the work. FARE also provided Lived Experience Advocates with access to the Employee Assistance Program, a professional counselling service for employees, and details for other support services.

FARE worked with Lived Experience Advocates to elevate their sense of agency, including by ensuring Advocates gave free, prior and informed consent to participate in the project. This involved ensuring Advocates had a thorough understanding of what the engagement involved, including the risks of harmful or unwanted outcomes. Prior to participating in the project, Lived Experience Advocates completed Informed Consent and Agency checklists developed by FARE to ensure fully informed consent was provided and Advocates had a full sense of agency in engaging in the project.

Stories of Lived Experience Advocates

**Names have been changed to protect anonymity.*

Tom*

Tom is a 55-year-old successful professional with lived experience of alcohol dependence. He has been sober since 2018.

Through his teenage years and early adulthood, Tom used alcohol as a coping mechanism for anxiety, stress and mental-ill health. Later in life, Tom's successful career masked his dependence on alcohol.

Tom experienced workplace bullying and PTSD, which led to an escalation in his alcohol use and dependence, and a breakdown in his relationship and family life. Tom's alcohol use had negative impacts on his wife and two young daughters.

Tom was diagnosed with pancreatitis, a life-threatening condition caused by high-level alcohol use. Doctors warned him he would die unless he stopped drinking. Tom tried rehabilitation several times but was unable to find a service that met his needs.

Tom's alcohol use and mental health issues intensified. He became increasingly isolated from his family, and he attempted suicide.

Eventually Tom reached a turning point, prompting him to sell his house, seek professional help, and relocate to a new environment. With five years of sobriety, Tom has experienced remarkable improvements in his life and relationships with his wife, family and friends and finding happiness and pride in his daughters' achievements.

Tom is passionate about helping people find employment after rehabilitation.

Zelma*

Zelma is a young person with lived experience of trauma, mental ill-health and high-risk alcohol use.

Zelma began using alcohol as a young person, as a coping mechanism for mental health conditions and trauma.

The heavy drinking of a former partner had a strong influence on Zelma, and she experienced periods of high-risk alcohol use and alcohol dependence in her early 20s.

Zelma has, at times, felt pressured by social norms and expectations around alcohol. She recognises the influence of alcohol marketing and media, which often depicts alcohol use as a solution to stress or negative events.

Zelma has reduced her alcohol use to improve her health and wellbeing, after learning more about the health impacts of alcohol use from her studies. She uses strategies such as avoiding having alcohol in the house and nominating to be the designated driver when out with her friends. Zelma's friends have been supportive of her efforts to reduce her alcohol intake, and she appreciates their understanding when she takes breaks

from drinking. However, she still sometimes finds it difficult to stop at one drink, and to avoid using alcohol in response to stressful events.

Zelma is passionate about harm reduction and helping young people manage mental-ill health.

Joan*

Joan has lived experience of family violence through the experience of a family member.

Joan's daughter was violently attacked by her partner after he had been drinking heavily. She suffered a stroke weeks after the attack, likely due to non-fatal strangulation. Her story highlights the long-term physical and emotional impacts of family violence.

Joan has advocated tirelessly for meaningful inclusion of lived experience in family violence policy development and decision-making processes. This has contributed to a paradigm shift in how government departments and organisations approach policy development.

Recognising the profound impact of family violence on children and young people, Joan stresses the need to include them in discussions surrounding policy and support systems. She highlights the importance of collaboration between lived experience advocates and decision-makers, and of reshaping Australia's cultural norms about alcohol.

Joan is passionate about regulating online sales and delivery of alcohol, and ensuring young people are protected from alcohol harms.

Emily

Emily is a 26-year-old young person with lived and living experience of navigating multiple cultures around alcohol. For Emily, alcohol use is shameful in one culture, while abstinence is socially unacceptable in the other.

As a child of Vietnamese and Malaysian immigrants in Australia, Emily experienced challenges reconciling their family's cultural expectations of abstinence from alcohol with the permissive drinking culture of their peers.

During adolescence, Emily faced pressure to conform to their parents' values while trying to fit in with their friends. Emily found it difficult to navigate the stark contrast between their family's fear of alcohol and their peers' permissive attitudes, and to deal with social pressures to consume alcohol.

At university, Emily began using alcohol at high levels, to conform with the heavy drinking culture among their social group and to rebel against their family's norms.

Emily also has lived experience as a young carer for family and friends with alcohol and substance use challenges and recovery.

Emily cared for friends who used alcohol at high-risk levels, and later for a partner experiencing alcohol dependence. Emily found it difficult to care for their own mental health and wellbeing without feeling guilt, and believes there is a need for more support for carers of people experiencing alcohol dependence or other harms.

Emily is also passionate about the need to support young people to have open conversations about alcohol use.

Angelene

Angelene has lived experience of alcohol dependence and trauma, and being a mother of a child with Fetal Alcohol Spectrum Disorder (FASD).

After a positive early childhood and family life, at the age of eight, Angelene experienced sexual abuse by a family member who was intoxicated. This caused Angelene significant trauma, and led to her experiencing low self-esteem, social withdrawal, and bullying.

Angelene began drinking in her teenage years, and found it helped her cope with the mental health impacts of trauma. Her drinking gradually increased during her twenties, when it progressed from a social activity, to drinking on her own at home, and eventually to alcohol dependence.

Following the trauma of her mother's diagnosis and death from a rare form of brain cancer, Angelene's alcohol use and dependence escalated. She was hospitalised after nearly dying from alcohol use, but she was not able to stop drinking due to her physical dependence on alcohol.

Angelene unexpectedly and joyfully became pregnant, after being told she would be unable to conceive without fertility treatment, at the age of 34. She was met with negative reactions and a lack of support when she disclosed her alcohol use and dependence to a health professional.

Angelene's son was diagnosed with Fetal Alcohol Spectrum Disorder (FASD) at the age of three. His early diagnosis has allowed him to have support in place from a young age, and he is now thriving at the age of 14.

Angelene's lived experiences of alcohol harm and as the parent and carer of a child with FASD have motivated her to advocate for increased awareness of the risks of alcohol use in pregnancy, empathetic and evidence-informed support for women who use alcohol in pregnancy, and improved support for children with FASD, and their parents and carers.

Angelene is a passionate, dedicated, and experienced advocate. She has spoken at conferences, in the media, and was involved in the successful introduction of mandatory pregnancy health warning labels on alcohol products in Australia. She is also involved with FARE's national *Every Moment Matters* campaign on alcohol use and pregnancy.

Tess*

Tess migrated to Australia in the 1980s and has two children. She has lived experience of alcohol harm and navigation of services through her son.

Her son has PTSD, experiences alcohol dependence, and has become violent while using alcohol. Tess has found it difficult to find integrated Alcohol and Other Drug (AOD) and mental health services that meet her son's needs and that offer holistic, wraparound support for her son and the family.

Being a carer for her son has caused stress and anxiety for Tess, but she has been supported by others with similar lived experience. Although her son's wellbeing has improved, worry about his future still weighs heavily on her mind.

Tess is passionate about improving the efficacy and efficiency of Alcohol and Other Drug (AOD) and mental health services, so that people can get help when they need it. She would also like to see greater involvement of the family in these services, and better data sharing so that different services can wrap around a person.

Tess also highlights the importance of early intervention and believes that schools should play a critical role in educating children about mental health and alcohol and substance use and dependence. More important, instead of punishing children (as they do), they should be proactive in identifying potential issues by accessing support through early intervention services.

Jessica

Jessica is an adult with living experience of FASD and lived experience of mental ill health.

Jessica experienced neurological, cognitive and social challenges as a result of her undiagnosed FASD, leading to secondary conditions and mental health issues. Although she grew up in a safe and supportive family, Jessica struggled with daily functioning and was unable to integrate with her peers leaving her isolated and confused. When she left home, there was no longer the familial scaffolding and support. This led to a deterioration of her wellbeing and challenges in thriving as a young adult.

Despite actively seeking help, Jessica's myriad symptoms were minimised or dismissed by health professionals, exacerbating her difficulties for more than a decade. It wasn't until the age of 33 that Jessica was finally diagnosed with FASD, thanks to her mother's research and determination.

Despite presenting as a bright and engaged individual, she relies on a multidisciplinary team of professionals to help support her with her functioning and the challenges associated with FASD,

Jessica's story underscores the challenges faced by individuals with undiagnosed FASD and the importance of diagnosis and support.

Driven by her lived and living experiences, Jessica has become a passionate advocate for awareness of FASD and the risks of alcohol use during pregnancy. Jessica firmly believes that medical professionals should play a vital role in providing accurate information and addressing alcohol consumption during pregnancy. She highlights the need for education and policy changes to help prevent FASD, and improved support systems and understanding for people with FASD.

Jessica is a passionate, dedicated, and experienced advocate. She has appeared in the media, and was involved in the successful introduction of mandatory pregnancy health warning labels on alcohol products in Australia. Jessica is also involved with FARE's national *Every Moment Matters* campaign on alcohol use and pregnancy.

Research Findings

Analysis of the Lived Experience Advocates interview transcripts revealed a diverse range of lived and living experiences of alcohol use and harms, many of which have had serious and long-lasting consequences for Advocates' physical and mental health and wellbeing. Advocates' experiences included direct harms from alcohol use, as well as alcohol harm experienced by family members, friends and loved ones. These experiences interacted with, or were influenced by, a range of other social and cultural factors, and policy and system issues.

Five key themes were identified from the Advocates' interviews:

1. Alcohol and mental health
2. Alcohol and family violence
3. Fetal Alcohol Spectrum Disorder
4. Alcohol and culture
5. Embedding lived experience of alcohol harm in policy making.

Theme 1: Alcohol and mental health

An almost universal theme of the Lived Experience Advocates' stories was the interconnected relationship between alcohol use and mental health. This was a key theme for Advocates who reported using alcohol as a coping mechanism in response to trauma and mental health issues, and who experienced negative mental health impacts from alcohol. It was also a theme for Advocates who experienced negative mental health impacts from caring for people affected by alcohol harm or dependence.

Advocates, Tom, Zelma, Angelene and Tess, have lived and living experience of the negative impacts of alcohol on mental health, and of the reciprocal relationship between high-risk alcohol use and mental health conditions, including anxiety, depression, Attention Deficit Hyperactivity Disorder (ADHD), Post Traumatic Stress Disorder (PTSD), and suicidal thoughts and behaviour.

Tom used alcohol as a child as self-medication for undiagnosed anxiety, and in response to workplace stress and bullying and harassment as an adult. His experiences led to him developing PTSD and alcohol dependence, and attempting suicide.

Angelene began using alcohol at high levels to help her cope with trauma from sexual abuse, and from her mother dying of brain cancer. This led to her developing alcohol dependence.

Zelma experienced anxiety and depression as a young teenager and was later diagnosed with ADHD and PTSD. She used alcohol as a coping mechanism and self-medication for these conditions.

Tess is a mother and carer of a teenage son who experiences alcohol dependence. She has lived and living experience of stress and anxiety from living with constant fear and worry about his wellbeing. Her son has also experienced mental ill-health linked to alcohol use and dependence.

The Advocates' experiences reflect the high prevalence of mental health conditions in the community, and the strong links between alcohol use and mental ill-health. Mental health issues affect nearly all Australians and Victorians – including people who experience mental ill-health themselves, and their carers, family members or friends. More than two in five Australians (44 per cent) have experienced a mental health condition in their lifetime,¹⁹ and one in five Australians experience mental illness each year.²⁰ Similarly, in Victoria, around one in five people have experienced mental illness in the last 12 months, and nearly half of Victorians will experience mental illness in their lifetime.²¹ The 2021 Victorian Royal Commission into Victoria's Mental Health System (Mental Health Royal Commission) reported that more than 1.1 million people in Victoria were expected to experience some level of mental illness or psychological distress in 2020–21, which could be thought of as someone in every family or close friendship group in Victoria.²²

The relationship between alcohol use and mental ill-health can operate in different directions, and in complex and multi-faceted ways, which is evident in the Advocates' stories. Often people use alcohol to help them cope with mental health issues – to seek relief from social anxiety, work or financial stress, family or relationship issues, poor sleep or low mood. People also use alcohol in response to psychological distress or trauma, or mental health conditions, particularly when they cannot get the treatment, care or support they need. However, alcohol is likely to worsen mental health, including by interfering with sleep, increasing feelings of sadness and

anxiety, causing deterioration in mental health conditions, and leading people to develop alcohol dependence or other alcohol use disorders.

For people who have a higher risk of mental health conditions such as anxiety or depression, alcohol use increases the likelihood they will develop the condition. People with mental health conditions or experiencing psychological distress are significantly more likely to use alcohol at high-risk levels than people who do not have these conditions or experiences. Alcohol can cause people with a mental health condition to experience a deterioration in their mental health and poorer outcomes.²³

The 2018 Australian National Health Survey found that men with mental health conditions were 15 per cent more likely to report consuming alcohol at high levels than the general population, and women were 10 per cent more likely.²⁴ According to the 2019 National Drug Strategy Household Survey, 27 per cent of people who were identified as being at high risk from alcohol use had been treated for or diagnosed with a mental health condition in the previous 12 months, compared to 16 per cent of the general population.²⁵

People with a mental health condition are also more likely than other people to have an alcohol use disorder.²⁶ Around 35 per cent of Australians living with mental illness are estimated to also have a substance use disorder.²⁷ Research reported by the Victorian Royal Commission into Victoria's Mental Health System indicates that around 50–76 per cent of people in Victoria who seek help from alcohol and other drug (AOD) services have at least one co-occurring mental health condition.²⁸

Alcohol and mental health in young people

Tom, Angelene and Zelma all spoke about their experiences of first using alcohol as teenagers to help them cope with mental health challenges. The Advocates relied on alcohol to help manage painful emotions and feelings stemming from their mental health conditions or past trauma.

Tom's alcohol use began at 12 or 13 years of age, when he started to use alcohol to ease feelings of shyness, and then to disinhibit and relax in social situations, and to seek relief from undiagnosed anxiety.

"Drinking alcohol brought me out of my shell a bit because I'm relatively shy by nature.

I always had anxiety as a kid, and even though it was never diagnosed, I found that if I drank, I didn't feel so anxious, it numbed my anxiety."

Angelene also began using alcohol as a teenager to escape from negative thoughts, resulting from her traumatic experience of sexual assault in her childhood.

"It silenced the judgy chatter in my head... I just wanted a quiet mind.

While everybody else was getting all excited about this alcohol, I was just thinking, 'Oh, goodness, is this what it's like to actually have a quiet head and not to be thinking about all of this grown up stuff."

As a young teenager, Zelma began seeing a psychologist after she had been self-harming and was diagnosed with anxiety and depression. She started using alcohol at the age of 12 or 13 to help her cope with these conditions.

Tess' son experiences alcohol dependence as a young person, which Tess believes is linked to mental health challenges.

“Physically he has no issues, but he has this cloud of mental health issues that leads to addiction.”

As was the case for the Lived Experience Advocates, young people who experience mental health problems are more likely to use alcohol. The 2019 National Drug Strategy Household Survey found that young people aged 16–24 who experienced high or very high levels of psychological distress in the previous 12 months were more likely to have used alcohol at high-risk levels compared to those with low levels of psychological distress.²⁹

Alcohol use also increases the risk of young people developing a mental illness. Research has found that initiating alcohol use at a young age (generally under 18 years) makes it more likely that a person will develop an alcohol use disorder, anxiety or depression during their life.³⁰ The more alcohol a young person consumes, the higher the risk that they will develop symptoms of depression. Drinking at high levels is also likely to exacerbate existing depression, especially in young women.³¹ Data from 2018–19 indicate that 61 per cent of young people aged 12–25 years who were being supported by AOD service providers had also been diagnosed with a mental health condition.³²

Alcohol as self-medication for mental ill-health

The Advocates' experiences provide illuminating real-world insights into how people who experience mental ill-health or trauma often use alcohol as a coping strategy or to self-medicate, which can ultimately worsen mental health, and lead to the development of, or exacerbate existing mental health conditions. Their experiences are typical of the common co-occurrence of mental health conditions with alcohol use disorders or dependence, and show how people can become trapped in harmful cycles in which their alcohol use and mental health conditions have reciprocal and mutually reinforcing impacts.

After being diagnosed with anxiety and depression as a teenager, Zelma was later diagnosed with PTSD and ADHD. She used alcohol to help deal with these conditions.

“For me, the mental health issues came first. Alcohol was a coping thing. In the moment, it makes you feel better. It was very much that I didn't want to handle these emotions. I didn't want to feel them.”

Zelma had been trying to reduce her alcohol use when she experienced a traumatic event. Her drinking then escalated in response to the trauma.

“We had a friend's 30th birthday. I drank a whole bottle of wine before we went out, and then started another one on the way there and then was severely sloppy.”

That was one of the few times my friends actually clicked on to how much I was drinking. Because I hadn't told them about the traumatic event.

They were like, What? What is going on? Why she this drunk? And then, when I was drunk, I told them about what had happened."

Zelma's experiences with alcohol now fluctuate. She generally avoids alcohol. However, she still finds it difficult not to use alcohol to help her cope with mental health challenges.

"My relationship with alcohol is still pretty up and down. It's definitely something that's been connected to my mental health and as a coping mechanism."

"Just last week, I lost my job. One of my first instincts was to get on it. I didn't, but it still crops up as an option."

"It sort of comes and goes in waves. More often than not, I'm just completely sober. Because I still struggle that if I have a drink, I can't just have one."

Tom used alcohol as a coping mechanism in response to stress and mental health impacts from his work in human resources, and workplace bullying and harassment.

"It's hard working in that role when you have to lay people off. It's not an easy job and it takes a toll on you mentally. I wasn't equipped for it. They don't prepare you at university for the human toll, not to mention the abuse.

"My way of coping with it was to have a few drinks to settle down."

Angelene's drinking increased when she started university, reinforced by a culture of heavy alcohol use. She used alcohol to help relieve social anxiety and bolster her low self-esteem, caused by her past trauma. This led to her drinking on her own at home, and gradually developing alcohol dependence.

"I found alcohol to be an interesting social lubricant because my self-confidence and self-esteem were very low from the previous trauma and harms."

"I started drinking quite a lot on Friday and Saturday nights."

"Then I started drinking when I went home, so we would all go home and everybody else would go to bed but I would stay up drinking. I didn't understand why at the time but that was the beginning of my dependence on alcohol."

Zelma's use of alcohol as a coping mechanism for mental ill-health was influenced by alcohol marketing and the media's normalisation of alcohol use to cope with stress or negative events.

"A lot of what impacted me, and my decisions was how everyone, in every show or movie, if they have a hard day, they go out for a drink."

This is consistent with research, which has found that alcohol marketing promotes and normalises the use of

alcohol as a coping mechanism for stress or other mental health issues. When stay-at-home restrictions were in place in Australia during the COVID-19 pandemic, sponsored social media advertising explicitly promoted the use of alcohol to cope, survive or feel better.³³ This reinforcement of alcohol use to cope with mental health issues can contribute to high-risk alcohol use, exacerbate mental ill-health, and lead to a cycle of negative outcomes.

Alcohol dependence

The Advocates' stories shed light on how experiences of psychological distress, trauma or mental health conditions may lead to people using alcohol at increasingly high-risk levels, and eventually developing alcohol use disorders or dependence.

Tom drank increasingly heavily to cope with experiences of work stress and anxiety, which led to him becoming dependent on alcohol.

“That few drinks became sneaking off at lunchtime to drink to take the edge off everything. I covered the smell and it worked for me. I got promoted.”

“I was promoted to a new role as the head of Australia and New Zealand for a multi-national company. About 18 months later, I became head of Asia Pacific.”

“I was hypersensitive but I just put on this armour, I was indestructible in my own mind. It was exhausting living like that.”

“That was when my drinking became really out of control.”

“I was hiding bottles of vodka all over the house. I was never violent, but I wasn't present.”

Tom attempted to stop drinking, but returned to alcohol when he was running his own business and working from home, which enabled him to drink constantly without fear of being caught by clients.

“I started running my own business, working from home. I was drinking every day. I was a functioning alcoholic who could lie through my teeth.”

Tom experienced bullying and harassment at work and developed PTSD, and his alcohol use escalated further. This led to the breakdown of Tom's relationship with his wife, and to Tom becoming isolated from his family and friends.

Tom's experience provides insights into the negative cycle that can occur when mental health conditions lead to or co-exist with alcohol use disorders or dependence. This may have a range of negative impacts on a person's life, health and wellbeing, affecting their daily functioning, family, relationships, work, finances, and long-term physical and mental health and wellbeing, and leading to social isolation. These impacts can exacerbate mental ill-health and entrench heavy alcohol use.

“I put in a PTSD claim through my income protection insurance and for the next two years, I stayed at home slowly drinking myself to death.”

“I didn’t go anywhere, didn’t socialise, didn’t do anything.”

“I was isolating, not wanting to engage, to see [my daughters] play netball, go to their graduations. Not wanting to do anything but drink. That was my life’s purpose.”

Angelene’s alcohol use and dependence escalated in response to stress from a demanding career, the breakdown of her relationship, and the devastating diagnosis and death of her mother with terminal brain cancer.

“My mum got diagnosed in January of 2006 with glioblastoma, which is a terminal brain cancer. It’s very aggressive.”

“That brought up for me, almost like a volcanic eruption of emotion. Basically, everything bubbled up to the surface. And I started drinking very, very heavily.”

“I was drinking 20–24 hours, seven days a week. So, if I was awake, I was drinking.”

“It wasn’t because I was enjoying drinking. I just wanted the effect that made things go away.”

“Alcohol was my crutch, my escape from the pain and grief.”

Angelene nearly died from alcohol use, but her physical dependence on alcohol meant that she was not able to stop drinking.

“Even after nearly losing my life, the first thing I did upon leaving the hospital was reach for another drink.”

Zelma’s experiences highlight the negative mental health impacts of having a partner who drinks at high levels. Research has found that women with partners who drink heavily experience higher levels of depression and anxiety and lower wellbeing,³⁴ and are more likely to experience an alcohol use disorder, than other women.³⁵ Zelma’s drinking was reinforced by the normalisation of high levels of daily alcohol use in her relationship, contributing to her experiencing periods of alcohol dependence.

“He drank a lot, and we would often drink when we were together. For me, it had normally just been sort of a weekend thing. And in my family, my parents didn’t really drink during the week. Whereas, he would always have a drink after work and stuff. And that sort of became normal. And then, it would be normal to drink a lot most evenings I was with him.”

“It was sort of a bottle each night, and then if I wanted more, a couple of beers or something. It was a bit easy to justify.”

Alcohol use, mental health and physical health

Tom's story also shows how alcohol use in response to mental ill-health can lead to serious short- and long-term impacts on a person's physical health and wellbeing. Tom's alcohol use caused him to develop life-threatening pancreatitis and diabetes.

"In 2015, I started getting terrible stomach pain. It turned out to be pancreatitis. The doctors were very abrupt. They said, 'you've got to stop drinking or you're going to kill yourself.'"

"The impact on my health is on-going"

"In 2019, I had to have half my pancreas removed. I was in intensive care for a couple of days, and it was a five- or six-hour operation."

"As a result of all that, I'm now a diabetic."

Alcohol use can have a range of negative impacts on people's physical health, which may also be detrimental to their mental health and sense of wellbeing. In the short-term, alcohol can cause drowsiness, nausea and vomiting, and more serious effects, such as loss of consciousness, and breathing difficulties. It can also affect the amount and quality of people's sleep and disrupt their sleep patterns.^{36 37} Poor quality sleep can have negative impacts on people's daily functioning, quality of life, and contribute to the development of mental health conditions.³⁸

In the long-term, alcohol use increases people's risk of developing serious health problems, including liver cirrhosis, pancreatitis, stroke, high blood pressure, heart disease and cancer. Regularly drinking at harmful levels can lead to alcohol-related brain impairment. Alcohol has been classified by the World Health Organization International Agency for Research on Cancer as a Group 1 carcinogen,³⁹ and is a proven risk factor for cancers of the mouth, throat (pharynx and larynx), oesophagus, liver, breast and bowel.⁴⁰ The more alcohol a person consumes, the higher their risk of developing cancer.⁴¹ Alcohol use is responsible for around 5,800 new cancer cases in Australia each year.⁴²

Alcohol use and suicide

Tom's story demonstrates how mental ill-health alongside alcohol dependence may lead to suicidal behaviour. After Tom developed alcohol dependence and his alcohol use became heavier, his mental health deteriorated further, his family relationships broke down, and he became increasingly socially isolated. This led him to contemplate, then attempt, suicide.

"One day I was on my way to work and, standing at the train station holding onto the wire thinking 'I'm going to jump.'"

"I couldn't keep going like that anymore. I called my boss, sitting in the backyard surrounded by cans and vodka bottles, and said I quit."

“For the next two years, I stayed at home slowly drinking myself to death. I didn’t go anywhere, didn’t socialise didn’t do anything.”

“My wife kicked me out of the house, and I went to stay with my father, who would lecture me about the dangers of drinking.”

“My brother came down and found me in the process of attempting suicide. He came at the right time.”

Suicide is the leading cause of death for people aged 15–44 years in Australia, and the second highest cause of death for people aged 45–65 years.⁴³ Men are three to four times more likely to die by suicide than women, and suicide rates are highest among men who are middle aged or older.⁴⁴ Each year in Victoria, around three-quarters of suspected suicide deaths are men, and most are aged between 25 and 54 years of age.⁴⁵

Tom’s experience reflects the role of alcohol and alcohol use disorders as significant risk factors for suicide attempts and suicide.^{46 47 48} The more alcohol a person has just consumed, the higher their risk of attempting suicide.⁴⁹ A person’s suicide attempt is more likely to result in their death if they have used alcohol in the time leading up to the attempt.⁵⁰

About one in five people who die from suicide have an alcohol use disorder,⁵¹ and people who experience alcohol use disorders are 2.6 times more likely to die from suicide than the general population.⁵² The risk of suicide increases if a person with an alcohol use disorder also has a mental health condition.⁵³ Young people living with FASD are twice as likely to experience suicidal ideation in adolescence than individuals without FASD.⁵⁴

Mental health impacts on carers

Two of the Advocates, Emily and Tess, recounted their stories of caring for people experiencing alcohol harm or dependence, and the mental health impacts they experienced themselves.

Studies show that carers who support someone with dependence on alcohol or another drug tend to experience poorer physical and mental health than other groups of carers.⁵⁵ Many carers find it hard to balance their own needs with the demands of caring for another person.

Tess, a mother of a son with alcohol dependence, described the stress, anxiety, and emotional burden of caring for her son.

“When you wake up at 10 o’clock in the morning and your son is holding a bottle of whiskey in one hand and has half of the glass in the other, and is already hardly walking or can hardly stand it up. It’s a tough gig.”

“It was really killing me. It was very hard. It was very hard to see someone completely out of control.”

The constant uncertainty and fear of what the future holds took a toll on Tess' mental health and wellbeing.

"What state is he going to be in and what's next? What are we going to get today? You were walking on eggshells all the time."

"I'm over 60 years old, and I don't see my son getting better in 20 years. At this point in time today, I don't have that hope."

Currently, Tess' son's living conditions are stable, and his wellbeing has improved. Tess receives support from another person with lived experience. This has provided her with some relief and helped her to cope with the mental health burden she experiences.

Tess' experiences demonstrate the importance of carers having access to a positive support system.

"I think today I can have more positive conversations with him. I was very well supported by a lived experience person through a different program, and you start dealing with the situation better."

"The positive part of him living in a stable place and everything is that I can hug my son today when he walks in. All those things they are in the past. I can have a decent conversation with him. It's more like it's easier to go and embrace him the way he is, without that day-to-day load of someone totally out of control and struggling."

"When the person is trying and there's a support system it becomes better because you know that you have hope. When there's nothing, you just don't know what your day is going to be."

As a teenager, Emily began acting as a carer for their friends who were harmed by alcohol. Several of their friends experienced alcohol poisoning, and two of their friends died while engaging in risky behaviour after using alcohol. Emily later became a carer for two of their former partners who were experiencing alcohol dependence.

"Growing up, I was so focused on looking after my friends that I often forgot to look after myself. I tried to balance them, but I ended up feeling like I failed at both."

"Some of my friends experienced alcohol harm at a really young age. Sometimes this looked like alcohol poisoning, relationship difficulties, or engaging in reckless behaviour. However, sometimes it looked like friends passing away because of the amount of alcohol they consumed."

"What I really needed was someone safe to talk to - someone that really understood who I was and where I came from. Even now, I still don't know any young queer people of colour that talk about their experiences of caring and alcohol harm. It's hard to get support if you feel so alone."

Emily's story highlights the need for greater awareness and support for young carers of people experiencing alcohol harm or dependence. Emily indicates that for many caregivers it is difficult to find resources and support to increase their knowledge about alcohol dependence, and how to care and seek treatment for someone who is affected.

“People like us just don’t know that there is support out there.”

“It’s a systemic issue, but I think that raising awareness is key to addressing it. We need to be more aware of lived experiences and the supports available.”

“I only found out about support programs because I now work in healthcare. I definitely wouldn’t have found out about these supports otherwise.”

This limited awareness and availability of support creates a challenging environment for carers, leaving them feeling guilty when they prioritise their own self-care. Emily reflected that as a carer, they were constantly questioning whether they were entitled to seek emotional support that was critical to their well-being.

“There’s often a lack of support for the person that’s directly experiencing alcohol harm. In my experience as a carer, I felt incredibly guilty if I talked about myself. I felt like I was adding to the problem or changing the spotlight onto me.”

“I was constantly advocating and trying to find support for the people I cared for – so much so that I often didn’t have enough time or space for myself. I felt really guilty reaching out because I felt like I should be spending my time and energy on the person I care for.”

Policy implications

Access to integrated mental health and Alcohol and Other Drug services

The complex and reciprocal relationship between alcohol use and mental ill-health highlighted by the Advocates’ experiences indicates the need for well-integrated and FASD-informed mental health and Alcohol and Other Drug (AOD) programs and services in Victoria that respond effectively to the needs of people with co-occurring mental health conditions and alcohol use disorders, and that ensure people can access appropriate treatment, care and support.

For example, Tom had several experiences with alcohol rehabilitation services and had difficulty finding a service that met his needs. Many of the services he tried were based on Alcoholics Anonymous (AA) principles, which were unsuitable for Tom, and did not help to address his alcohol use and mental health issues.

“I’d been in rehab for a month here and a month there. Nothing seemed to work.”

He described one experience of a rehabilitation service as “like military school”.

“I did a month there and I just found it soul destroying. They kept telling us it was an illness, but then talking to us like we’re doing it on purpose.”

Eventually Tom found a ‘detox’ service that offered a psychiatrist and cognitive behavioural therapy, which was effective in supporting him to stop drinking.

“Something just clicked. I haven’t had a drink since.”

Zelma spoke about feeling fortunate that her parents were able to afford mental health support for her.

“I am very lucky that my parents were able to afford all of it. Even with a mental health care plan, we were still paying. Plus, it was only the 10 sessions, which is not a lot. Otherwise, I would have been more likely to turn to a service like AA. I would have had less choices.”

In attempting to help her son navigate the health and justice systems, and access appropriate treatment and support, Tess has experienced firsthand the lack of integration of services and systems.

“This is the problem with the system. Again, they are operating in silos. You would have been picked up here by the justice system, but due to privacy legislation, the hospital doesn’t know.”

Tess is passionate about the need for integrated and coordinated support for young people dealing with alcohol use and mental health challenges, and their families.

“There should be only one point of contact within the system as they meet the person for the first time.”

“Someone that can look at the person holistically and with the family. Someone that says “I want to talk to your parents here. I want to get your full story.” That’d be amazing. That wraparound support.”

The need for better integration of AOD services and mental health services, and to ensure people experiencing alcohol and substance issues or dependence are not excluded from mental health treatment, were key recommendations of the 2021 Final Report of the Royal Commission into Victoria’s Mental Health System. The Commission found that Victoria’s mental health system has deteriorated over many years, and many people with alcohol use disorders and mental health conditions face significant barriers in accessing appropriate and coordinated care, with services not sufficiently integrated. The Commission found that instead, people are required to navigate two separate AOD and mental health systems that do not provide coordinated care for their interrelated needs. Often people are bounced between different services; excluded from mental health services because they lack expertise and capacity to provide support to people experiencing harm from alcohol or substances; or turned away from AOD services because they cannot provide treatment and support for mental health conditions. This is also very detrimental for people living with FASD who also have an alcohol use disorder and mental ill-health, as they need consistent and familiar support.

The Commission also heard evidence about the high levels of co-existing alcohol or substance use and mental health and wellbeing challenges for young people, and the need for young people to have integrated care and support.

The Commission made several recommendations to improve integration of services and care for people experiencing mental ill-health and alcohol or substance use issues, including the establishment of a state-wide specialist service to provide primary care to people with complex support needs, and to support practitioners and clinicians working across the AOD and mental health sectors to deliver joined-up care. The Commission also recommended that new community-based mental health and wellbeing services, bed-based services, and

crisis and emergency services should all provide integrated treatment, care and support to people with co-occurring mental health and alcohol or substance use conditions.⁵⁶

The Victorian Government has committed to implementing all the Royal Commission's recommendations, and has begun initial work towards better integrating mental health and AOD services. This has included work towards establishing a new state-wide AOD and mental health specialist service as recommended by the Royal Commission. The Government has also published guidance for mental health and AOD services, setting a shared vision and framework for system integration,⁵⁷ and has developed a workplan, setting out how it will implement the recommended reforms to deliver integrated care.⁵⁸ These are important first steps, but there is still significant work needed to ensure all people in Victoria experiencing mental health and alcohol use conditions can access coordinated and holistic care that meets their needs.

Support for carers

Carers play a crucial role in supporting people experiencing alcohol use disorders and mental ill-health. The value, experiences and needs of carers must be recognised and addressed within the AOD and mental health systems, and carers must have improved access to support.

Tess underlined the importance of a holistic approach to caring for people with mental ill-health and alcohol dependence that actively involves their families, carers and support networks. She explained that existing systems and services fail to acknowledge and draw on the experience of carers and families, or to provide integrated support that includes them in care and decision-making.

There's no one basically saying "Let's work together. Let's bring your people. Let's bring everybody, let's bring your partner. Let's have this discussion on how we can support you so you can start moving forward."

As a young carer of friends experiencing alcohol harms, Emily would like other young carers to have access to platforms and networks to enable them to talk about their experiences, and access support. They believe there is a need for greater awareness of the caring role that many people play.

"I want other people to see that there are spaces to talk about our experiences, that there is support available."

"I want people to feel less alone and more okay to talk about our experiences."

It should be recognised that carers may have their own challenges with mental or physical health, and caring for friends and family members who have complex needs can be detrimental to their own wellbeing, as described by Jessica.

"For years I supported a friend with a serious mental health condition who was in an alcohol/drug fuelled domestic violence situation. She would turn up at my house needing help; I would bathe/feed her, take her to emergency, support her in her court hearings etc. However there was no help for her as services weren't linked and she had no money or family support...the relationship became dangerous for me and I had to end it without successful intervention".

The Final Report of the Royal Commission into Victoria's Mental Health System emphasised the valuable role of families, carers, and support networks in caring for people with mental health and alcohol use conditions, and their need for recognition and support within the mental health system.

The Commission heard of similar experiences of carers of people with mental health conditions, finding that the system excludes carers and fails to support their caring role. Many carers need support in their own right but are unable to access it, and there is a lack of information and awareness about the support available.

The Commission highlighted the need for the system to shift from an individualistic approach, which does not consider the social context in which people live in the community, to a holistic approach, which recognises the role of a person's family, carers and support network. This should include involving families, carers, and supporters in care and recovery as standard practice throughout the system, and providing dedicated support to those carers. The experience and expertise of carers, families and supporters should be elevated in re-designing the system.

Additionally, the Commission recommended the establishment of family- and carer-led centres in each region of Victoria to provide tailored information and support, and access to funds for immediate practical needs, such as short-term respite. These centres should also facilitate the formation of family and carer peer support groups.

The Commission also recognised the role of young carers and recommended that they have access to tailored supports across Victoria. Funding should be provided to organisations to co-design and broaden the range of supports for young people caring for family members or others with mental health conditions.⁵⁹

The Victorian Government has committed to implementing these recommendations.⁶⁰

Preventing the impacts of alcohol on mental health

The Advocates' stories highlight the interrelationship between alcohol use and mental ill-health, and the importance of preventing alcohol harm for improving the mental health and wellbeing of people in the Victorian community. Despite these strong links between alcohol use and mental ill-health, alcohol is often missing from public conversations and policy making about mental health. Much greater attention to the relationship between alcohol and mental ill-health is needed in education, program and policy responses to improving mental health and wellbeing in Victoria.

In response to recommendations of the Royal Commission into Victoria's Mental Health System, the Victorian Government has established a Mental Health and Wellbeing Promotion Office, which has responsibility for developing a Statewide Wellbeing Plan. The Plan will aim to shift the focus of the mental health system from treatment and care towards prevention, promotion and healing.⁶¹ To be successful in doing so, it will be critical that the plan includes a focus on effective policy reforms and programs to address the role of alcohol in influencing poor mental health outcomes in the community.

The Victorian *Public Health and Wellbeing Plan 2019-2023* identifies reducing harmful alcohol and drug use as one of ten priorities along with improving mental wellbeing.⁶² However, alcohol and drug use was not identified as a focus area. Preventing alcohol harm, including mental health impacts from alcohol use, should be an important focus area in the next four-year plan that will be in place from 2024. The plan should include a range of evidence-based policies to reduce alcohol harm in Victoria, including higher standards for alcohol marketing that prevent alcohol companies promoting alcohol as a coping mechanism for mental ill-health.

Theme 2: Alcohol and family violence

The story of Lived Experience Advocate Joan illuminates the significant long-lasting impacts of family violence on victim survivors and their families, and the complex and harmful role that alcohol can play in family violence.

The causes of family violence are complex and deeply rooted in society, stemming from power imbalances caused by harmful cultural norms, gender inequality and rigid gender stereotyping. While alcohol is not a direct cause of family violence, and never excuses a family violence perpetrator, it can be a significant risk factor that exacerbates family violence.

Australian and international research has established a clear association between alcohol use and the frequency and severity of family violence.^{63,64,65} This was acknowledged by the 2016 Final Report of the Victorian Royal Commission into Family Violence, which identified alcohol as a contributing factor to family violence, based on evidence that alcohol can exacerbate the severity of family violence and the psychological harm that it causes.⁶⁶

Family violence is common across socio-economic and demographic groups in Victoria and Australia, predominantly affecting women and children.⁶⁷ Alcohol is involved in a high proportion of family violence cases. Between 23 per cent and 65 per cent of police reported family violence incidents in Australia are estimated to involve alcohol.⁶⁸ Of the more than 90,000 family violence incidents reported to Victorian police in 2021–2022, alcohol use by the perpetrator was recorded as a factor in more than one in five (22 per cent) cases.⁶⁹

Impacts of family violence

Joan has witnessed firsthand the devastating impacts of family violence on her daughter and her daughter's children. The violence was perpetrated by Joan's daughter's former partner, who used alcohol at high-risk levels.

“My daughter was very, very violently attacked by her partner.”

“He was a very heavy drinker. He would begin to drink when he got home on a Friday night and just continue to drink for the whole weekend. It was on a Friday night that he attacked her.”

“He threw her up against a wall and was strangling her and the teenage children intervened and were able to pull him off. He then grabbed a knife and was going to kill them.”

“They’ve barricaded themselves in a bedroom and called police.”

The violence that Joan's daughter experienced has had ongoing traumatic and emotional impacts for her and

her children, as well as serious long-term consequences for her physical health. Joan's daughter, who had just completed her nursing training, suffered a stroke weeks after the attack, likely linked to non-fatal strangulation.

"The consequences of that have been very traumatic for her, for her children."

"Subsequently there were charges and court appearances and things like that, which was a terrible thing to go through."

"But probably the worst thing on top of it all, just a matter of weeks after that attack, my daughter then suffered a stroke."

"It's become quite evident recently from research that there's a well proved connection between non-fatal strangulation and the potential for stroke within the next few months."

The physical and emotional effects of the violence on Joan's daughter have made it impossible for her to pursue her long-term dream of becoming a nurse. In addition to ongoing physical and psychological impacts, the family violence has impacted on her career and affected her family's financial circumstances.

"The very sad thing about that, too, was that she just finished retraining as a nurse, which was something she'd wanted to do all her life. She'd been working and holding the family together and providing the stable income for the home."

"For my daughter, it doesn't just become an issue of trying to get her life back together, but she's lost a dream that she had, and she will never really be able to do that now. She's just not physically or emotionally capable of pursuing that career."

"All the things that you might have dreamed about and thought you could be, or gave you passion or purpose in your life, have been destroyed as well. So, it's a bigger thing than just the event of violence or some of the surrounding issues."

The role of alcohol in family violence

Joan's story illustrates the complexity of the relationship between alcohol and family violence, and the need for deep understanding and care in the way the role of alcohol is addressed and described. Joan was emphatic that alcohol should never be used or framed as an excuse for family violence.

"I hate hearing it used as an excuse."

"I don't believe that overconsumption of alcohol should ever be seen as an excuse for dangerous and often fatal behaviour."

"It's not an excuse for what they did."

Joan explained that the causes of family violence are complex and deeply embedded. However, she does

regard alcohol as a high-risk trigger or tipping point for both family violence and sexual violence, and believes alcohol can exacerbate family violence due to its disinhibitory effects.

“I think it could be a trigger like many other things, like losing your job or financial difficulties or the death of a child. Any of these things can be triggers, but the causes of family violence are much more complex and much deeper than those external influences on people’s lives.”

“I think it’s fairly well accepted that your level of self-control is diminished by the amount of alcohol that you’ve consumed. I think that opens up all sorts of risks and dangers to people, not only in the family violence area, but certainly in the sexual violence area as well.”

“It really could be that tipping point at any one moment in time. For my daughter, this wasn’t the first time that that her husband had been drinking and it wouldn’t have been the last.”

Policy implications

Royal Commission into Family Violence

The Victorian Royal Commission into Family Violence was established in 2015, following a series of deaths from family violence in Victoria.

The Commission heard evidence from many other women whose lives had been shattered by family violence, and families whose loved ones had been killed. The Commission described these personal accounts of people’s lived experience as fundamental to its consideration of measures to reduce the risk of family violence and respond to the needs of those affected.

In its Final Report in 2016, the Commission made 227 recommendations to reduce the impact of family violence on the Victorian community, all of which the Victorian Government committed to implementing. The recommendations included whole-of-government policy and structural reforms and programs to help prevent family violence, reforms to improve legal, health system and government responses to family violence, and measures to significantly improve family violence support services. They also included measures to embed the voices of people with lived experience of family violence in policy- and decision-making processes, such as the establishment of the Victim Survivors’ Advisory Council.

In relation to the role of alcohol as a contributing factor in family violence, the Commission recommended that a review of Victorian liquor legislation (the *Liquor Control Reform Act 1998*) consider family violence and alcohol-related harms, including consultation with people with expertise in the relationship between family violence and alcohol use.⁷⁰

The Victorian Government has implemented the Royal Commission recommendations, and has done significant work to prevent family violence, and support the many Victorians who continue to be harmed. However, reforms have not included effective safeguards to reduce alcohol as a risk factor in family violence.

A review of the *Liquor Control Reform Act 1998* (Liquor Act) was undertaken between 2016 and 2022, which

included family violence in its terms of reference.⁷¹ Following the review, the definition of harm in the Liquor Act was broadened to explicitly refer to family violence. However, rather than introducing controls on alcohol availability, the Liquor Act was amended to expand the types of liquor licences that are authorised to supply alcohol online for take away and home delivery, and to extend the ordinary trading hours of all alcohol venues (pubs, bars and nightclubs) from 11pm to 1am (meaning that licence applicants are no longer required to apply for a specific late-night licence to trade until 1am).⁷²

In addition to this, a Victorian Government freeze on new licence applications for alcohol venues to trade later than 1am in inner city areas of Melbourne, which has been in place since 2009, will be lifted from 1 July 2023.⁷³

Alcohol availability and family violence

Joan believes the constant availability of alcohol in Victoria contributes to its role as a risk factor and trigger for family violence and abuse. Joan is particularly concerned about the risks presented by online sales and home delivery of alcohol due to its potential to fuel violence in the home, especially at night.

“Many of the stories that I’ve heard from other advocates and victim survivors of both physical and sexual abuse, is that the availability on a constant basis of alcohol so it’s almost like there’s never a moment where it’s not available.”

“It’s a 24/7 kind of situation with online deliveries and ordering.”

Joan spoke about the increase in online sales and home delivery of alcohol, which accelerated during COVID-19 stay-at-home restrictions in Victoria. Alcohol companies used the pandemic as an opportunity to expand online sales and alcohol delivery to people’s homes, and liquor licensing laws were loosened to allow a broader range of licensed premises, including restaurants, cafés and clubs, to home deliver alcohol.

The increase in online sales and delivery of alcohol has continued following COVID-19 restrictions, and is a long-term trend across the country. Annual revenue from online alcohol sales in Australia has quadrupled from \$539 million in 2012 to \$2 billion in 2022. This rapid expansion of online sales and delivery is continuing, with the revenue from Australian online alcohol sales forecast to grow at an annual rate of 10.6 per cent to 2026-27.⁷⁴

Joan’s concerns about the risks of online sales and delivery of alcohol are supported by significant research. Victorian and Australian studies have found that people who order rapid alcohol delivery are likely to use alcohol at extremely high-risk levels, and most are already intoxicated when they receive their delivery.^{75, 76, 77, 78} A 2023 Australian survey found that people who had alcohol delivered were six times more likely to use alcohol at harmful levels than other people.⁷⁹

Joan is also concerned about risks from late-night alcohol venues, such as pubs, bars and nightclubs. She expressed her disappointment about the lifting of the freeze on new late-night licensed premises trading after 1am in inner city Melbourne. She is worried this will lead to more late-night venues in Melbourne, and an increase in family violence.

“I found that quite disappointing because I don’t see that as making Melbourne a better place, extending the length of time that people can continue to drink.”

“I could quote some stories about what it’s like for women late at night when the perpetrator comes home, after having perhaps been out for a night of drinking, and then can still

continue to drink because the availability is there.”

Joan’s concerns about late-night alcohol trading are borne out by evidence. A substantial body of Australian and international research has established that extending hours of alcohol trading at night leads to increases in violence.^{80, 81, 82, 83} Research has also found that assaults involving alcohol increase substantially between 6pm and 3am at night.⁸⁴

Joan believes restricting the availability of alcohol in Victoria, including the hours of alcohol trading and delivery, should be a first step in addressing the involvement of alcohol in family violence.

“I think limiting the hours of availability or even some of the conditions of availability has got to be one of the first steps that we could make. And I think we could do that quite easily.”

Theme 3: Fetal Alcohol Spectrum Disorder

Two of the Lived Experience Advocates, Jessica and Angelene, have lived and living experience of Fetal Alcohol Spectrum Disorder (FASD). Jessica is a young woman with FASD, and Angelene is the mother and carer of a 14-year-old child with FASD.

FASD is a lifelong disability caused by a developing baby being exposed to alcohol in pregnancy. Any alcohol consumed during pregnancy crosses the placenta and passes directly to the developing baby. This can affect the development of the brain and other organs and systems of the body and can lead to FASD. Any amount of alcohol increases the risk of irreparable harm to a developing baby. However, the risk increases according to the frequency and amount of alcohol consumed.⁸⁵

The prevalence of FASD in Australia is largely unknown. However, FASD is believed to be one of the leading causes of preventable disability in Australia,⁸⁶ and that as many as two per cent of babies born in Australia may have FASD⁸⁷ In the 2019 National Drug Strategy Household survey, more than half (55 per cent) of Australian women surveyed consumed alcohol before knowing they were pregnant.⁸⁸ Other Australian studies^{89,90} have identified that 60 per cent or more of women consumed alcohol while pregnant, many at risky levels, before becoming aware of their pregnancy.

People with FASD may experience a range of physical, neural, behavioural and cognitive challenges, such as:

- physical and emotional developmental delay
- issues with motor skills
- impaired speech and language development
- physical health issues
- sensory and auditory processing disorders
- difficulties with emotional regulation, adaptive functioning and social skills
- challenges with executive functioning, impulse control and hyperactivity, and
- issues with learning, memory and attention.⁹¹

People with FASD can also develop secondary conditions resulting from difficulties they experience, such as depression, anxiety, behavioural issues and substance use disorders. More than 400 conditions have been identified as co-occurring with FASD.⁹²

Since FASD is a spectrum disorder, it affects people in different ways, and each person with FASD has unique strengths and challenges. Most people with FASD experience difficulties with daily activities and need additional support throughout their lives. Early diagnosis, intervention, and access to support services, leads to improved outcomes for people with FASD.⁹³

Impacts of undiagnosed FASD

Jessica's story provides insights into the challenges and impacts for people living with FASD, especially if they are undiagnosed and not receiving appropriate support.

FASD caused Jessica to experience neurological and social challenges throughout her childhood, and major difficulties with executive functioning, and mental and physical ill-health in her early adulthood. Jessica was not diagnosed with FASD until the age of 33.

Living with undiagnosed FASD had profound impacts on Jessica as a child. She found it difficult to integrate with her peers and participate in group activities. She often struggled to understand what was going on around her and would become withdrawn and anxious. Unable to keep up with other children, she became ostracised and grew up lonely and isolated.

"I'm privileged in so many ways... My mother provided a loving, supportive and stable environment. She worked so hard to give me everything I needed, but I was a very sad, confused kid just trying to be accepted and do well...it was very hard, I masked many of my difficulties. I was often blamed for my difficulties. We didn't know about FASD and neither did the health professionals it would seem. If I had been diagnosed as a child, my experience would have been profoundly different."

"I felt acutely lonely growing up. I didn't have a lot of friends, as I didn't integrate well with peers, and it only got worse as I got older. I blamed myself and internalised my perceived failings... it destroyed my confidence and self esteem."

When Jessica left high school, she no longer received scaffolding and support with her executive functioning challenges. At the same time, she moved out of home and had increased adult responsibilities. Jessica struggled to manage her responsibilities, causing stress and a decline in her functioning and wellbeing.

"There was a slow but steady decline in my functioning and mental health from the moment I left home at 18. I didn't have the same familial support. I was supposed to 'adult'. I wanted to 'adult', but without the right scaffolding in place, that is near impossible for a person with FASD."

"I understood what my responsibilities were, I knew what was expected of me...often this brain injury is described as the difference between what you know, and what you can do with what you know. For me this is very true and has led to a lot of frustration and despair."

"I fell through the cracks, because I present well. I have strong language skills, I was enthusiastic and polite. I didn't have extreme behavioural issues. I masked well. too well. People thought I was capable of managing the increasing demands and responsibilities of my age, but I was fundamentally unable to do so without support."

Jessica's FASD, and the significant challenges she experienced, led to her developing serious physical and mental health conditions, including chronic fatigue, postural orthostatic tachycardia syndrome (POTS), and severe depression and anxiety.

“My childhood and adult life has been fraught. I’ve had countless traumatic, scary and humiliating experiences as a direct result of this brain injury. I also missed out on many positive fun experiences, and it has created a deep sense of loss and grief that I have had to come to terms with - what could have been if I didn’t have FASD.”

“Because no health professional could identify that I had a brain injury, I started to have a lot of secondary problems and co-morbidities, the candle was being burnt at both ends and I developed severe myalgic encephalomyelitis ME/CFS, POTS, depression and anxiety. I can look back now and see that anxiety, depression and fatigue was always a problem for me, but when I hit adulthood things got really bad.”

“In my 20’s I was trying to match my peers, constantly. The physical and cognitive effort I needed to expend to try to keep up was immense and it truly nearly killed me. I’m still in recovery from the damage it caused.”

“One of the main issues with FASD is it causes damage to the central nervous system. It affects the way that your organs function.”

Diagnosis of FASD

Jessica and Angelene both experienced significant challenges with obtaining FASD diagnoses. Their experiences highlight the lack of awareness of FASD among some health professionals, and the importance of health professionals being informed and trained in relation to FASD to enable early diagnosis and intervention.

Angelene was aware that her son was at risk of being born with FASD, due to his prenatal alcohol exposure. She researched FASD, but the little information she found focused on facial features. This led her to think any FASD symptoms would be physically obvious.

“I couldn’t find much about FASD at the time, I could find things on the internet, and they were all about sentinel facial features and markers and things like that. So as far as I was concerned, I was going to be looking for something very obviously physical.”

Looking back, Angelene realises there were early indications that her son had FASD.

“He was a small baby. He needed a feeding tube in for 48 hours. He needed oxygen for the first 24 hours. And it took what seemed like an eternal lifetime for him to take his first breaths. So, he needed a bit of help when he was born. That was the first indication, and it was probably the most terrifying moment of my life.”

“It was also the happiest day of my life as well when my child was born.”

“And then after that he had a low suck reflex, which is quite common for children with FASD. He also had a little bit of trouble settling, and a lot of trouble with sleep. Sleep is a really big problem for kids with FASD, and he was no exception.”

“The first indication came when, at the age of two, two and a half, we noticed his language was quite delayed. Children of his chronological age were speaking a lot more fluently.”

It took multiple visits to health professionals before Angelene’s son was eventually diagnosed with FASD at three years of age. Despite his early signs of FASD and prenatal alcohol exposure, he was initially diagnosed with autism. Angelene puts this down to a lack of FASD awareness and similarities between the conditions.

“We took him to a paediatrician, and [he] did know about the prenatal alcohol exposure. However, even with that information, his first diagnosis was autism and that’s really super common. FASD is super good at mimicking autism.”

“I didn’t think that was right. He didn’t have any of the traditional stimming, lack of eye contact, that kind of stuff. It just didn’t quite fit.”

“No one’s to blame here. Awareness is low. This is why we’re trying to create awareness.”

Feeling unsure about the diagnosis, Angelene took her son to a FASD-informed paediatrician. After learning of Angelene’s son’s alcohol exposure in pregnancy, the paediatrician quickly diagnosed him with FASD.

“The next paediatrician was FASD informed, and he took down his prenatal exposure to alcohol. He then had a quick look at his receptive language reports and things like that and it was really less than five minutes. He said, ‘I don’t need to go any further. This is FASD. It’s not autism.’”

The experiences of Angelene’s son demonstrate the importance of early diagnosis and intervention.

“My son was diagnosed at three, which is considered quite early.”

“Diagnosis was paramount in getting the interventions and accommodations that he really needed on board in order to have the excellent outcomes that he’s having today.”

“From there, I was able to get speech therapy and occupational therapy happening.”

“He doesn’t have the secondary disabilities that come with a non or misdiagnosis.”

However, Angelene also described the difficulty she experienced in disclosing her son’s prenatal alcohol exposure, due to fears of stigma.

“It was so, so difficult to disclose my alcohol consumption, his prenatal alcohol exposure. However, it meant that he was able to get the correct diagnosis.”

For Jessica, it was a long and difficult path to diagnosis. Jessica’s mother researched Jessica’s symptoms for five years after becoming fearful for her daughter and determined to find an explanation for her health problems. Eventually she raised the possibility of FASD with Jessica.

“My mum became quite fearful for my safety. She felt that not only had my mental health deteriorated to a point where she was scared about me harming myself, but she was also scared that I was so deeply unwell that there was some illness that was going to get me.”

“Mum hit on FASD. I didn’t discover FASD, I didn’t know anything about FASD, I would have never considered it. My mum came to me and said, ‘I think you have FASD, and I think that’s why we’ve had so much trouble clarifying what’s happening for you.’”

Jessica began actively seeking a diagnosis, but it still took a further four years before a FASD diagnosis was confirmed. Jessica attributes this to a lack of FASD awareness among health professionals and the public.

“And from then, it was quite an arduous process. Even just hitting on FASD wasn’t straightforward because the information is not well known.”

“To actually obtain the diagnosis took four years after that.”

“It’s not really out there. It’s just not in the public consciousness.”

Health professionals minimised her many physical symptoms, explaining them as symptoms of depression or anxiety. Jessica still feels upset that health professionals’ dismissal of her symptoms led to her developing secondary conditions, which has had long-term negative impacts on her health.

“I had pages of symptoms! Gut motility issues, nausea upon standing, light and sound sensitivity, severe fatigue, brain fog, iron deficiency, heart palpitations, visual aberrations, peeling fingernails, migraines. weak/sore joints, breathlessness, insomnia, restless legs, hormone imbalance, weight loss, hair loss - the list went on and on...my doctor refused me referrals to specialists, and I was told that my symptoms were psychosomatic. All the symptoms that I was dealing with were minimised.”

“I really suffered through my 20’s. I don’t mean to be melodramatic by saying I suffered but I cannot express in words how bad my situation was, how difficult this was and how unacknowledged and poorly treated I was by my doctor at the time. I wouldn’t wish this experience on anyone, and this is why I speak.”

“I don’t think anyone should have to go through what I went through to get the diagnosis and be so gaslit, so ridiculed, so scoffed at and so dismissed, and become so sick because of it. I’m still dealing with the consequences of it 10 years later. That’s unacceptable.”

Like Angelene, Jessica spoke about the importance of early FASD diagnosis, and health professionals being informed about FASD. When Jessica was eventually diagnosed, and began to receive appropriate support, it was life changing.

“Diagnosis is the only reason I’m functioning and able to be here with you speaking to you. There was no way forward, there was no access to support, I didn’t even know what support I needed.”

In 2021, the Australian Senate Community Affairs References Committee released its final report on its inquiry into *Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder* (FASD Senate Inquiry).⁹⁴ Much of the evidence heard by the Inquiry reflects the lived experiences of Jessica and Angelene.

The FASD Senate Inquiry heard that early diagnosis of FASD is crucial because it enables early intervention, with therapies such as speech therapy and occupational therapy, and supports for behaviour and learning, which

can improve long-term outcomes for people with FASD. Without diagnosis and support, people with FASD have a higher likelihood of developing secondary conditions, and requiring greater education, health and mental health support. However, as was the case for Jessica, people with FASD are often not diagnosed early in life, and sometimes not at all.⁹⁵

The Inquiry also heard that misdiagnosis is also common for people with FASD, as highlighted by Angelene's son's experience. As many as 80 per cent of people who are eventually diagnosed with FASD are previously misdiagnosed with another disability or disorder. Consequently, many people with FASD do not receive the support they need early in life.⁹⁶

Support for people with FASD, families and carers

Jessica's and Angelene's stories highlight the importance of people with FASD receiving appropriate support, and illustrate the level and multidisciplinary nature of support they are likely to need. Both Jessica's and Angelene's experiences also provide insights into the work and persistence that can be required to access the right support, with not all health professionals trained in FASD.

Angelene's son has a National Disability Insurance Scheme (NDIS) plan that covers speech therapy, occupational therapy and psychology, and he will soon start equine therapy to help him deal with anxiety. Angelene had to be proactive in educating health professionals about FASD interventions to get the best outcomes for her son. She gives credit to the health professionals who listened to her advice and took FASD courses to upskill.

"I needed to provide a lot of documentation and videos to actually train the speech therapists on what specific FASD interventions would look like. The same with the occupational therapist."

"They completely modified what they were going to do with my son because they were going to do ASD based interventions. Both admitted that just would have been a circus. We would have had tables flipped, we would have had door slamming, and we would have got absolutely nothing."

"They started implementing interventions that kids have normally grown out of by three or four when he was seven and eight. And that worked really, really well."

To their credit, they really took it on board. They went and upskilled. They actually took courses on FASD themselves.

Jessica also receives a high level of support from a large multidisciplinary team, which she needs to help her manage the impacts of FASD, and support her daily functioning. However, she noted that many people with FASD require a higher degree of support.

"At the moment I am working with an occupational therapist, neuropsychologist, a psychiatrist, an art therapist, and exercise physiologist, and that's to help with the chronic fatigue. I have a social worker on occasion as well. Then I have support workers that come in

and help me.”

“I have quite a big team of people and that is quite common. Individuals with FASD need multidisciplinary skills.”

While Angelene’s son’s primary school was able to accommodate him, Angelene experienced considerable difficulty finding a high school for her son that would accept him and support his needs. He is now enrolled in a virtual school, which has made accommodations to support him.

“There was literally nothing for him in high school. He’s unable to attend the mainstream high school.”

“If you have autism, you get an exemption to be able to get into special schools on the basis of adaptive functioning and sensory issues and stuff like that. That’s not applicable for FASD.”

“Virtual schools accepted him. They have developed a half workload for him. He can be by himself and interact whenever he needs to. But he can’t hear any class chatter or any school noise from anywhere else in the school.”

“It’s worked out really well for him.”

Angelene’s son is now thriving, and his early diagnosis and intervention means he is likely to have positive long-term outcomes. However, Angelene is aware that he will still need support throughout his life.

“He will need to be accommodated, almost certainly, for the rest of his life. This is lifelong.”

Angelene’s and Jessica’s lived experiences are consistent with evidence heard by the FASD Senate Inquiry that people with FASD require extensive support throughout their lives. Because of the variability and range of the challenges people with FASD experience, they need personalised care programs delivered by multidisciplinary teams.⁹⁷

Children with FASD often need support with behaviour, social and emotional skills, and life and education skills, including support with daily activities. In addition, their families and carers of children may need education and capacity building to help them understand and support their child, as well as support with daily activities, and their mental and emotional wellbeing. Adults with FASD may also need a range of supports, including support with financial management, interpersonal and living arrangements, workforce training and vocational support, and specific support for people who are parents.⁹⁸

Support and advice on alcohol use and pregnancy

Angelene’s lived experiences during her pregnancy highlight the need for health professionals to be informed about guidelines on alcohol use and pregnancy, and to provide judgment-free guidance, care and support.

Angelene became pregnant while still experiencing alcohol dependence, after being advised she would be unable to conceive without fertility treatment.

“I was told that without IVF I wouldn’t be able to conceive. I had zero chance of conceiving a baby.”

“When I did the first pregnancy test and it turned positive, I did the other two in the packet and then went and bought another packet. I’ve still got six pregnancy sticks lined up and they were all positive and I couldn’t believe. The feelings were elation, surprise, in a really good way, which was then followed up by absolute sheer horror because I was drinking about two bottles of wine a day.”

She saw a gynaecologist and disclosed that she was experiencing alcohol dependence and drinking at high levels. However, the gynaecologist failed to offer appropriate support to help her safely reduce her alcohol consumption. Instead, he instructed Angelene to immediately stop drinking, which would have had dangerous consequences for her and her developing baby.

“Upon finding out that I was pregnant, I took myself off to a gynaecologist straightaway. I let him know that I was an alcoholic in recovery, and that I was also in relapse, and I was drinking. I was in full flight. I was drinking 24/7, two bottles of wine a day.”

“I laid it all out on the table and the response I got was that’s banned from the baby.”

“You need to stop doing that and you better be stopped before you come back and see me again.”

“That was definitely not the right advice for someone who’s physically dependent on alcohol. Had I walked out and done that, it would have been life threatening, both for myself and my child.”

“For anybody that’s physically dependent on alcohol, just stopping abruptly is life threatening, and you really do need medical intervention.”

This negative experience deterred Angelene from disclosing her alcohol use to other health professionals during her pregnancy. However, she took all the steps she could to have a healthy pregnancy. While she could not stop drinking entirely, she was able to reduce her alcohol intake.

“It didn’t matter if another health professional was more empathetic or compassionate. I was not prepared to go through that again. Throughout my pregnancy I needed to go to appointments, but I didn’t disclose again.”

“I have RH negative blood, so I needed to have anti D shots. I didn’t eat soft cheeses, I didn’t drink coffee. I didn’t do all the stuff you’re not supposed to do. And the one thing I couldn’t do was to stop drinking alcohol entirely.”

“I tried really, really hard to cut down to one bottle or seven to eight standard drinks a day. That was pretty much as low as I could go. But every time I went under that, I’d then try to jump completely off, and within two or three days, I would need to go to hospital because I

would be spotting.”

Angelene spoke passionately about the need for women who have used alcohol in pregnancy to be treated with empathy and compassion, and offered appropriate support from health professionals without fear of judgment, shame or stigma.

“Everybody needs to understand that there are women that are physically dependent on alcohol like myself. It doesn’t mean they don’t love their children. In every case it almost certainly means that the woman herself has experienced some kind of trauma.”

“That’s a message I’d really like to get across. Prenatal alcohol exposure is never malicious. We love our children.”

Angelene believes there is a need for greater public awareness and conversations about prenatal alcohol exposure and FASD to address the significant stigma that exists, and to support people to be able to speak openly about alcohol use in pregnancy to health professionals. She hopes sharing her story will help.

“There’s an awful lot of stigma out there, and there just shouldn’t be stigma. It’s very difficult for everybody in society to talk about prenatal alcohol exposure and that includes health professionals, it includes your paediatrician, it includes your gynaecologist. FASD is very stigmatised, yet it is the most prevalent cause of developmental disability and delay, not only in Australia but on the planet.”

“Nobody wants to talk about it because it involves prenatal alcohol consumption and exposure. But we need to move past that.”

“I hope that sharing my story helps other women out there to say, ‘I didn’t know, I went to a party before I found out I was pregnant, and I drank.’”

Policy implications

Improving diagnosis of FASD

Based on their lived experiences of the importance of FASD diagnosis, Angelene and Jessica both emphasise the need for funding and policy changes to improve diagnosis of FASD in Australia.

Angelene is passionate about the need for early FASD diagnosis to enable early interventions and support, which improve long-term outcomes for a child with FASD.

“The earlier that a child can get diagnosed, the earlier interventions can come on board, and the better the outcomes can be for the child.”

“With the appropriate diagnosis, interventions and supports, it certainly doesn’t need to be a

life sentence for either you or your child.”

Similarly, Jessica’s lived experience has motivated her advocacy for improved FASD diagnosis.

“That’s why I do care deeply about the power of diagnosis and why I advocate very strongly for the need for diagnosis, for medical professionals to be informed, because it makes or breaks your life. It truly does.”

The Final Report of the FASD Senate Inquiry reported on a range of factors contributing to lack of diagnosis or misdiagnosis of FASD in Australia. It heard that diagnosis of FASD is complex, time consuming and requires a multidisciplinary team of health professionals with specialist skills. However, it is difficult to access these FASD diagnostic services, due to limited availability, long wait lists and high costs. These barriers can be exacerbated for people in rural, regional and remote areas, on low incomes or with language or literacy challenges. The Inquiry found that access to FASD diagnostic services is fragmented, poorly funded and lacking in a whole-of-government approach.⁹⁹

Other barriers to diagnosis include health professionals’ lack of awareness of FASD diagnostic criteria and services, their reluctance to discuss alcohol use in pregnancy with their patients, and a shortage of health professionals trained to diagnose FASD.¹⁰⁰ As Angelene experienced, negative responses and fear of stigma can also deter patients from disclosing alcohol use in pregnancy and make FASD diagnosis more difficult.

The Committee made several recommendations to improve access to FASD diagnosis in the community, including:

- developing a long-term sustainable funding model for FASD diagnostic services
- exploring alternative models for FASD assessments
- building the capacity of the workforce involved in FASD diagnosis by investing in training, and ensuring FASD is part of relevant university curricula, and
- disseminating FASD diagnosis guidelines and training health professionals to use them.

The *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018–2028* aims to reduce the prevalence and impact of FASD, and the quality of life for people living with FASD. Priority objectives of the Plan include improving health professionals’ FASD diagnostic skills and knowledge, and improving FASD diagnosis and screening capacity.¹⁰¹

In 2020, the Australian Government announced \$24 million in funding over four years from 2020–21 for FASD diagnostic and support services. Part of this funding is being used to expand FASD diagnostic services in regional Victoria.¹⁰²

While this investment will help to improve access to diagnostic services, significant work is still needed to build the knowledge and capacity of health professionals involved in FASD diagnosis and to further expand FASD diagnostic services.

Improving support for people with FASD and carers

The lived experiences of Jessica and Angelene highlight the importance of all people with FASD having access to necessary support.

The FASD Senate Inquiry reported that the level of support needed by people with FASD, and families and carers, can be difficult to access, as services are limited and costly. The Inquiry heard about challenges families and carers experience in finding appropriate support services and meeting the extensive costs. This included difficulties in accessing support through the education system, NDIS and social security system. In addition, FASD is not currently recognised as a disability in Australia, which limits the support available to people with FASD and families or carers.¹⁰³

The difficulties Angelene experienced in finding a secondary school for her son demonstrates the need for improved support for FASD in schools, including accommodations or specialist secondary schools that are suitable for children with FASD.

“Secondary schooling for kids with FASD. I think we certainly need to look at it in Victoria.”

This was consistent with evidence presented to the FASD Senate Inquiry that the education system is not equipped to provide appropriate support to children with FASD.¹⁰⁴

Angelene’s experiences also provide important insights into the challenges experienced by families and carers of people with FASD, and their need for support themselves. The FASD Senate Inquiry heard that parents and carers of children with FASD can themselves experience significant impacts, including stress, the burden of care, unmet needs, and a diminished quality of life. This can be compounded by the lack of understanding and awareness of FASD within the community. Carers frequently find themselves having to explain their child’s behaviours and advocate for their child’s needs, contributing to their overall burden.¹⁰⁵

For Angelene, ensuring the right support was in place for her son was a huge undertaking, and required her to repeat her traumatic story multiple times to new health professionals.

“Whilst I’m super glad that that’s all in place, it was an awful lot of work for one mum.

It meant that every single time someone doesn’t know, I have to tell my whole trauma story all over again to try and explain it to them.”

As was the case for Angelene, parents and carers often face challenges in engaging the necessary supports for their child after receiving an FASD diagnosis, which may include difficulties completing paperwork, navigating unfamiliar service systems, managing the demands of raising other children, and coping with emotional burden and stress.

To improve support for people with FASD and families or carers, the Inquiry recommended:

- reforms to improve access to early childhood intervention and NDIS support for children with FASD
- including FASD in the list of recognised disabilities in Australia
- broadening eligibility requirements for the Disability Support Pension to include some people with FASD
- professional training of educators and resourcing to ensure all schools can support students with FASD
- funding programs for parents and carers, and
- increasing funding to support carers of children with FASD.

The Committee also made recommendations to improve support for people with FASD in child protection, correctional facilities and the justice system.

Prevention of FASD

The National Health and Medical Research Council's *Australian guidelines to reduce health risks from drinking alcohol* (Australian Alcohol Guidelines) advise that people who are pregnant or planning a pregnancy should not drink any alcohol to avoid the risk of harm to the developing baby.¹⁰⁶ However, Australia has one of the highest rates of alcohol use in pregnancy in the world. The 2019 National Drug Strategy Household Survey found that more than half (55 per cent) of Australian women surveyed consumed alcohol before knowing they were pregnant, and 14 per cent of women continue to drink after finding out.¹⁰⁷

Angelene emphasised the need for increased awareness of the Australian Alcohol Guidelines to improve FASD prevention.

“About half of our pregnancies are unplanned, so it’s very easy to drink alcohol before you find out that you’re pregnant. It’s definitely not malicious.”

“On the prevention front, we need to provide clear and consistent messaging that there is no safe limit of alcohol during pregnancy.”

“A really non-judgmental, compassionate, empathetic, but factual and honest approach is the best.”

Angelene’s views are supported by the FASD Senate Inquiry, which found there are low levels of awareness in Australia of FASD, the Australian Alcohol Guidelines, and the risks of alcohol in pregnancy. The Inquiry heard that people receive mixed messages about alcohol use and pregnancy from health professionals and peers.¹⁰⁸

In 2021, a survey of almost 1500 Australian women who were pregnant or planning a pregnancy found that one in three (29 per cent) were unaware that alcohol use during pregnancy could cause FASD. More than half (51 per cent) were not aware, or not sure, that alcohol could harm the developing baby, even in the early stages of pregnancy.¹⁰⁹

The Australian Government funded a national awareness campaign on alcohol use during pregnancy and breastfeeding, which was launched in 2021 and will run until 2024. The evidence-based ***Every Moment Matters campaign***, developed by FARE and endorsed and funded by the Australian Government Department of Health and Aged Care, aims to increase Australians’ awareness of the risks of alcohol consumption during pregnancy and breastfeeding, including FASD, and to support Australian women not to drink alcohol while pregnant or breastfeeding.

In another significant policy development, the Australian members of the Food Ministers Meeting (formerly Forum on Food Regulation) voted in 2020 to support a mandatory evidence-based health warning label about the risks of alcohol use in pregnancy on all packaged alcohol products. Alcohol manufacturers were given a three-year period (until 31 July 2023) to implement the label on all products.

These developments represent substantial progress towards increasing awareness of the risks of alcohol use in pregnancy, and FASD, and supporting alcohol-free pregnancies. However, there is a need for sustained funding for awareness raising and public education to ensure these strategies are effective to reduce the incidence of FASD. The FASD Senate Inquiry recommended a longer-term strategy and funding for national awareness and education.¹¹⁰ The Inquiry also recommended that this should also include FASD awareness and education in secondary school curriculums, a proposal strongly supported by Jessica.

“In the Senate Inquiry, there was a recommendation for there to be FASD education during sex education for teenagers. I think that is brilliant. Get them aware in school, just when they’re first starting to explore sex, and you can really hone that message in that time.”

“You can really solidify for young girls that pregnancy and drinking does not mix.”

Health professionals

Health professionals, especially those involved in pre-conception and antenatal care, have a key opportunity to provide information to women who are pregnant or may become pregnant about risks from alcohol. Jessica emphasised the need for professional development for health professionals to support them to provide accurate and consistent messages to women, consistent with the Australian Alcohol Guidelines.

“I care deeply about having medical professionals on board telling women the right information.”

“We can’t get it into the public consciousness and have a successful shift unless we have the medical profession on board.”

“We’ve got heaps of medical professionals that are really on board. But it’s definitely not enough, it’s not the majority. The medical professionals that see the public on a daily basis, I think they need better training, so they are comfortable enough to give the right information.”

Evidence supports Jessica’s views. Australian research has found that health professionals do not routinely ask pregnant women about alcohol use.^{111, 112} This can be because: they lack knowledge about the risks and harms; they have incorrect views that alcohol can be safely consumed; they believe women would already have been informed, or it is irrelevant to them; or they are worried about damaging patient relationships or stigmatising women.^{113, 114, 115} When women disclose alcohol use, health professionals may instead offer reassurance and downplay the risks.¹¹⁶

The FASD Senate Inquiry heard that health professionals involved in pre-conception and antenatal care often fail to advise women about harms of alcohol use in pregnancy, and that alcohol and FASD is inadequately covered in health professional and medical training and education. The Inquiry recommended that building the capacity of health professionals to advise women about alcohol during pregnancy should be prioritised, and funding should be provided for professional development training for all health professionals involved in antenatal care.¹¹⁷

Angelene’s lived experiences highlight that this should include training on how to support women experiencing alcohol dependence in pregnancy, including how to safely reduce and withdraw from alcohol use, and how to care for women in a non-stigmatising way.

There has been recent progress in building health professionals' awareness and capacity. The Every Moment Matters national awareness campaign has a stream focused on educating and upskilling health professionals to advise and support women on alcohol use and pregnancy. As part of the campaign, FARE has developed a range of evidence-based resources and training for health professionals.¹¹⁸ However, more work is needed to embed training on alcohol use in pregnancy and FASD in health professionals' training and professional development.

Measures to reduce alcohol use and harm in the community

Prevention of FASD must include policy measures to address the significant influences on women to consume alcohol, including alcohol marketing that targets young women. Prevention efforts should also focus on reducing the widespread availability of alcohol in the community, and changing cultural norms to ensure women are better supported to have alcohol-free pregnancies.

Jessica expressed her strong concerns about alcohol marketing that targets young women. She believes marketing of alcohol as a coping mechanism for women, particularly when they have young children, increases the risks of alcohol-exposed pregnancies.

“The marketing towards women, pink drinks, the idea of wine to relieve stress, wine as a medicine. I think all of that marketing and messaging is pretty toxic -the way that it targets women to use alcohol as a coping tool. Women often need extra support and tools to relieve stress when they are new mothers or have young children. For the alcohol industry to use that vulnerability as a way to market alcohol as that ‘tool’ is, in my opinion, vile..”

Angelene described the risks presented by online alcohol marketing, sales and delivery, which she believes is a driver of alcohol harm, and FASD. She is concerned that the increase in online sales and delivery of alcohol during the COVID-19 pandemic is likely to have led to an increase in children born with FASD.

“I see online delivery and the lack of regulations, coupled with advertising, as a massive driver of alcohol harm. I think that by 2025 and 2026 due to the pandemic, we are going to have an extremely large amount of children with undiagnosed FASD entering our primary schools, and that is going to be a big problem in the next couple of years.”

The FASD Senate Inquiry heard evidence of the widespread availability and pervasive culture of alcohol use in Australia, which influences attitudes and behaviour surrounding alcohol use in pregnancy. This is driven by factors including the low price of alcohol, the high numbers of alcohol stores in local communities, online sales and delivery, and alcohol marketing, all of which contribute to higher levels of consumption and harm. Similar to the concerns expressed by Jessica, the Inquiry also heard that alcohol marketing deliberately targets women in age groups in which they may become pregnant.¹¹⁹

The Inquiry agreed that population-level measures to reduce the price, availability and marketing of alcohol are needed to reduce alcohol harm in the community, and help prevent FASD, recommending that the Australian Government, as a matter of priority, implement alcohol marketing, pricing and taxation reforms.¹²⁰

Theme 4: Alcohol and culture

Cultural norms and attitudes towards alcohol vary greatly between different societies and groups, and are influenced by a range of factors, including religious beliefs, cultural traditions, and social customs, along with structural and environmental factors, such as the availability, price and marketing of alcohol.

In Australia, alcohol is widely available, and prevailing cultural norms and attitudes to alcohol tend to be permissive. Alcohol use is normalised and encouraged in a variety of social situations and settings, and high-risk drinking is often accepted and celebrated. However, while these are common cultural norms and behavioural patterns in relation to alcohol use, Australia does not have a single, homogenous alcohol culture. Instead, it has a diverse range of cultural norms in relation to alcohol that operate across different social worlds, and which interact and shift over time and across generations. People are likely to experience a network of social and cultural factors that influence whether and how they use alcohol, and their risk of experiencing harm.^{121, 122}

Cultural normalisation of alcohol

Most of the Advocates spoke about their experiences of the cultural normalisation of alcohol in Australia, and the influence of this on alcohol use and harms.

For example, Angelene made the following comment about Australia's alcohol culture:

"We live in Australia, we live in a drinking culture. We live in a place where alcohol is the only thing you need to justify not taking."

Joan expressed her concern that there is too much social acceptance of the relentless availability of alcohol, which stems from dominant cultural norms in Australia that reinforce alcohol use. She thinks more work is needed to challenge these norms and change the public narrative about alcohol.

"I think that there's been too much of a general acceptance over many, many years that drinking is just a part of who we are as Australians. I think we can change that message, that it doesn't have to be a part of our national identity."

"Even when you go overseas, our reputation has gone before us, and we're seen as heavy drinkers."

"I think if we could change that messaging and present an alternative. What does an Australian look like that doesn't have to drink, that doesn't have to always, you know, get on the beer when they're at the barbecue?"

Cultural pressure for young people to use alcohol

Many of the Advocates' stories highlight the social and cultural pressures young people experience to drink alcohol, throughout childhood, adolescence and early adulthood. They show how different social groups and settings have cultures that normalise high-risk alcohol use, increasing the likelihood of young people experiencing harm.

Although there has been a long-term decline in the proportion of young people aged 12–17 years in Australia who use alcohol, a very high proportion still drink. In 2017, almost half (46 per cent) of young people in this age group had used alcohol in the past year, and more than a quarter (27 per cent) had consumed alcohol in the past month.¹²³ The Australian Alcohol Guidelines recommend that children and young people under 18 years should not drink any alcohol due to the risks of injury and other harms to their health, including interfering with brain development, accidents, injury and self-harm, and developing alcohol use disorders or dependence later in life.¹²⁴

Young people aged 18–24 years in Australia are more likely than any other age groups to drink at high-risk levels. More than two in five people aged 18–24 years (41 per cent) use alcohol at levels that put them at short-term risk of harm (more than four alcoholic drinks in one sitting) at least monthly, and people in this age group are the most likely to drink at very high-risk levels (11 or more standard drinks on one occasion) at least once a month.¹²⁵ The Australian Alcohol Guidelines warn of higher risks from alcohol for young people aged 18–25 years than older adults, due to adverse effects of alcohol on young people's developing brains, and higher risk taking behaviour among this age group.

Young people aged 18–24 years are also more likely than other adults to report harms from the alcohol use of strangers, friends and co-workers.¹²⁶

In a 2016 Australian qualitative study of young people's alcohol use, a key reason given by young people aged 12–17 years for using alcohol was fitting in with social norms. Young people who participated in the study reported wanting to drink to fit in with peers, and described drinking as part of the culture. Some participants also reported using alcohol to cope with depression and unhappiness.¹²⁷

This is consistent with Emily's experiences of cultural pressure to use alcohol to fit in with their peers as a teenager and young adult. Emily's story provides insights into the challenges this can present for people with diverse cultural backgrounds and experiences. As a child of Vietnamese and Malaysian immigrants to Australia, Emily experienced strong cultural expectations from their parents not to use alcohol, which conflicted with the cultural normalisation of alcohol, and social pressure to drink from their peer group at school.

"I grew up in a very predominantly white and monocultural community. I was one of very few kids of colour in my school year group. I grew up feeling very different and not having many people to relate to."

"There were my friends who were very almost stereotypically Australian - whose parents would have a beer or wine in the afternoon whilst they watched the footy. In my home culture, I was told that alcohol was evil and I was honestly terrified of my friend's parents because I thought they regularly engaged in something that was inherently evil. None of it made sense."

"My closest friends started drinking around age 14, which was pretty standard for the kids of

our age at that time. There was this party at the beach where I was first offered alcohol, but I didn't have any because I was absolutely terrified."

"I ended up caving to the peer pressure and I had my first kind of drink at 16. To be honest, I thought that it tasted awful and I was confused about what the hype was about."

"I was just really trying my best to fit in. That was very hard when everyone else was drinking and I was the only one that wasn't."

Zelma also experienced pressure to use alcohol to conform with her peer group. She believes cultural normalisation of alcohol use by young people contributed to her drinking, and helped shape her identity as the "party animal" of her friendship group.

"Young people want to do things their parents don't want them to. So, we go ham, and then by the time we're old enough to do it legally, we're all just sending it. Everyone's doing it, and the people who don't are the weird ones."

"Sometimes it's hard to be objective because it's like, 'Oh, I'm young, I'm supposed to be doing this. It's fine.'"

"I did have that reputation in the friend group as the wild one. I'd be a party animal. I was always a liability."

Tom's experiences demonstrate how use of alcohol to help relieve anxiety and stress can be encouraged and reinforced by societal and cultural norms and attitudes to alcohol use in different settings and life stages, beginning from a young age. For Tom, this occurred through his family experiences and parents' role modelling of alcohol use in childhood, through the normalisation of alcohol use in his peer group in adolescence, and through a culture of heavy alcohol use at university and at the start of his career.

"A lot of my early drinking was driven by the culture of the time."

"I started drinking when I was 12 or 13. My mum and dad always used to have dinner parties and my brother and I would drink their alcohol."

"Then as a teenager, it was a social thing in my friendship group, going out on weekends and drinking."

"I played football and after the season you'd be drinking at breakfast when on football trips, it just became a normal thing."

"Drinking continued at university and when I started my career in human resources."

Emily also described their experiences of the alcohol culture in their social group at university, which normalised and celebrated high-risk alcohol use and harm.

"When I went to university, alcohol was still this big thing that everyone else was engaging in. I saw uni as my first opportunity to make my own choices and I decided I'd try my best to be

a part of the alcohol culture. So, I did it to a ridiculous extent. I was studying engineering and first-year engineering students are possibly the wildest people I've ever met."

"I joined that kind of culture where people were trading beer for water and it always felt uncool to be sober."

"Everyone was some level of intoxicated at all hours every day. Before classes and before exams, you would just go have a jug of beer at the university tavern. It was incredibly unhealthy and there was little to no understanding of alcohol harm or risk."

"People were constantly affected by different levels of alcohol poisoning. It was considered a joke or funny if you had to go to the hospital and get your stomach pumped. It was very terrifying, but I was doing my best to just feel 'normal'."

Similarly, Angelene was influenced by the culture of high-risk drinking in her friendship group at university.

"When you go off to university, there's a bit of a drinking culture."

"The people in my friendship group were drinking quite a lot and I started drinking quite a lot on Friday and Saturday nights as well."

The Advocates experiences at university are consistent with Australian research, which has found that a high proportion of university students use alcohol at high-risk levels, indicating strong cultural norms of high-risk drinking. In a study of 7,237 undergraduate students at an Australian university, 90 per cent had consumed alcohol in the previous 12 months and 34 per cent met criteria for high-risk drinking. In the four weeks before the survey, six per cent of students surveyed (434 students) had been assaulted by others who were drinking, and one per cent (72 students) had been sexually assaulted.¹²⁸

Alcohol marketing

Alcohol marketing plays a major role in creating cultures that celebrate and normalise alcohol use. Alcohol companies aggressively market alcohol as integral to all aspects of people's lives, including in family, social, sporting, educational, work and cultural settings. Young people are constantly exposed to, or targeted by, alcohol marketing in their everyday lives.¹²⁹ A large body of research has established that children and young people's exposure to alcohol advertising is associated with them starting to use alcohol at a younger age, and drinking at higher risk levels.^{130, 131 132 133}

A key marketing strategy for alcohol companies is partnering with and sponsoring sporting and other major events and festivals, many of which are aimed at young people. Emily has worked with a range of wellbeing and sporting organisations, and festivals, and has been aware of several partnerships with big alcohol companies. They believe this has an influence on promoting and normalising cultures of high-risk alcohol use among different social groups.

“I work in the mental health and wellbeing space. I’ve seen so many big organisations or events that have partnered with alcoholic organisations.”

“Particularly in the mental health and wellbeing space that is so underfunded, it makes sense that partnering with alcohol organisations would be good for funding. However, I think there need to be some more ethical considerations about some partnerships..”

Emily’s views are supported by research showing that alcohol sponsorship is effective in creating associations between social contexts and alcohol, encouraging positive attitudes to alcohol, and increasing high-risk alcohol use.¹³⁴

Zelma is also aware of the way alcohol marketing helps to normalise high-risk alcohol use by young people, and contributes to cultures of alcohol use among social groups. She has noticed endorsements of alcohol brands by celebrities and social media influencers popular with young people, as well as collaborations between beer breweries and punk and indie bands she follows on social media.

“I heard an ad recently which had Matt Corby on it, and it was for whiskey.”

Zelma’s insights are consistent with research, which has found that digital marketing of alcohol, including use of social media influencers, influences young people to use more alcohol, and is likely to increase harms.¹³⁵ Alcohol companies increasingly target young people with sponsored social media posts, using data about their interests and behaviours to develop highly tailored and targeted advertising. They also use celebrities and social media influencers, and peer-to-peer marketing to reach people with advertising for alcohol products and brands that friends have liked.¹³⁶ An Australian study found that young people who ‘like’ or follow alcohol marketing pages on social media are more likely to use alcohol at risky levels.¹³⁷

Young people in Australia, including people younger than 18, are targeted by alcohol advertising on social media platforms. An Australian study analysed Facebook advertising seen by 16-to-25-year-olds, and found that nearly one in five (17 per cent) of the underage participants in the study reported regularly seeing targeted alcohol advertisements in their Facebook feeds, and a further 41 per cent reported seeing them sometimes. Many participants had been flagged by Facebook’s advertising model as having alcohol-related interests, or had their data uploaded by alcohol companies, including some participants younger than 18.¹³⁸

Tom spoke about how alcohol marketing presents risks for people experiencing alcohol dependence, by triggering alcohol use and interfering with recovery. As a middle-aged professional man, Tom is targeted with online advertising for premium spirits, and beer advertisements when watching football. While he does not find this triggering now, he acknowledged that he would have during his recovery from alcohol dependence.

“Say I’m watching TED talks on HR or something like that, you see ads for scotch, vodka, Canadian Club, focused towards the middle class professional.”

“Then I could start watching stuff on footy. So of course, I’m gonna get the beer ads.”

“I’m watching the football. And then there’s a bunch of guys having a beer watching the footy, kicking back. You know, what if I’ve just come out of rehab and I’m watching the footy. Now, when rehab didn’t work for me, that would have triggered me.”

Zelma spoke about the ubiquity of alcohol advertising in the community, and the challenges this presents for people trying to avoid or reduce alcohol use.

“You can’t get away from it. It’s even on a bus stop near my home, which is on the same street as a primary school.”

Research supports the Advocates’ views. Studies have found that alcohol marketing can heighten positive emotions about alcohol, and trigger cravings for people with, or at risk of, alcohol dependence.¹³⁹

Alcohol normalisation and availability

The widespread availability of alcohol in the Victorian community makes it easy for people to access alcohol and contributes to its normalisation across multiple dimensions of people’s lives. For the Advocates, alcohol was ever-present in settings such as at home, at social events and celebrations, and as part of university, work and sport.

Zelma described how the normalisation and constant availability of alcohol makes it challenging to limit alcohol use.

“There is a lot of, “Oh, we’ll go for a drink, let’s catch up for a drink, let’s go to the pub. That does get a bit old.”

“When I have been to festivals and events, the bars don’t sell non-alcoholic drinks. You have to go elsewhere to get a soft drink or water.”

Tess spoke about how low alcohol prices, increasing numbers of alcohol stores, and online selling and home delivery of alcohol, enable people, including her son, to readily access alcohol.

“Access to alcohol today is a lot cheaper. When I arrived in Australia... spirits were expensive. Even wine, for you to get a good drop, you would have to pay a lot more money than you pay today. And there would probably be less places selling it.”

“Now Uber delivers everything. So, if you buy it online, they’ll just deliver it and all you need to do is take a question on if you are 18.”

Tess’ insights are supported by data on increases in alcohol availability and supply in Victoria. Alcohol companies have opened increasing numbers of alcohol outlets and venues across Victoria, including a rapid increase in large chain alcohol stores,¹⁴⁰ and there are now more than 24,000 active liquor licences in the state.¹⁴¹

Alcohol companies have also dramatically increased their investment in online alcohol sale and marketing, and alcohol home delivery, which has become a major mode of alcohol supply in Australia, and has made alcohol more accessible in people’s homes.¹⁴² Alcohol companies bombard people with copious amounts of digital advertising, and most digital advertising for online alcohol retailers contains a ‘Shop Now’ button, providing a direct link for people to purchase alcohol from their phones and have it delivered to their homes.¹⁴³ Many alcohol retailers offer alcohol delivery in under two hours, which research has found is associated with high-risk alcohol use.^{144 145 146 147} This model influences people to make impulsive alcohol purchases, and to have

alcohol delivered in short timeframes when alcohol supplies run out, presenting heightened risks for people experiencing mental health or alcohol use challenges.

Policy implications

Education and support for young people

Emily spoke passionately about the need for improved education and support for young people, and greater empathy and awareness, to help them manage pressures to use alcohol. They believe this should focus not just on the physical and biomedical impacts of alcohol, but also the mental health and emotional impacts.

Emily recommends that alcohol support services should be better tailored for young people “to meet them where they’re at” and provide safe spaces for young people to discuss alcohol issues in an open way. This should include an emphasis on storytelling and story sharing by young people from diverse communities to ensure people hear from others with similar identities and life experiences. In addition, Emily suggests that support services could facilitate mentorship and role modelling to support young people experiencing pressures, challenges and harms from alcohol.

Zelma spoke passionately about the need for better mental health and alcohol education and support for young people. She would like to see this education beginning in primary school or early high school.

Culturally appropriate services

Emily is also passionate about the need for more inclusive and culturally appropriate education, support, and services for alcohol. Emily believes these services should focus on prevention and early intervention, and provide holistic and compassionate support. Emily recommends a higher level of investment in AOD services to support the same progress they are seeing in the mental health system. This should include ensuring AOD services are informed by a deep understanding of diverse and intersectional perspectives, and how a person’s health and wellbeing is affected by intersectionality of culture, sexuality, gender, disability and other factors. To help achieve this, Emily believes there is a need for development of more diverse and representative AOD workforces, including leadership.

“I can’t stress enough about how important early intervention and prevention is. When it comes to alcohol harm, we need to start awareness and action as early and holistically as possible.”

“I think that Alcohol and Other Drugs is often considered like the ‘poor younger sibling’ of mental health.”

“I think there are a lot of recommendations that I’ve seen implemented really well in the mental health space that are applicable to alcohol harm. An example is intersectional understandings of health and wellbeing, which means understanding that your health is going to be affected by your sexuality, your gender, your culture, your disability, etc. Applying

that to an alcohol and drug space makes complete sense.”

“We need more lived and living experience workforce members. We also need more diverse staff that can address specific needs and identities. This change needs to start at the top of organisations like Boards and Executive Staff, but it also needs to be driven from the bottom too.”

Emily’s views on the need for more culturally appropriate AOD services are supported by data showing that people from diverse cultural backgrounds are under-represented in AOD treatment services.¹⁴⁸ This is understood to be due to people experiencing barriers in accessing services, such as racism, and lack of cultural understanding and appropriate language services and resources, rather than people having lower need for AOD treatment. Although some culturally diverse communities have lower rates of alcohol use compared with the general population, some groups within these communities are at higher risk of alcohol harm, such as people who are asylum seekers and refugees, particularly young people.¹⁴⁹

Research also supports Emily’s views about the need for AOD, mental health and other health service providers to improve understanding of intersectionality, and address barriers experienced by people from diverse communities when seeking treatment and support. For example, a national survey found that nearly 34 per cent of LGBTIQ+ people reported ‘usually or occasionally’ hiding their sexual orientation or gender identity when dealing with services to avoid discrimination and abuse.¹⁵⁰ The Royal Commission into Victoria’s Mental Health System heard evidence that LGBTIQ+ people report negative experiences of Victorian health and mental health services, ranging from ignorance to prejudice and discrimination.¹⁵¹

Aboriginal and Torres Strait Islander peoples in Victoria also experience barriers in accessing AOD treatment and support services, including a lack of culturally safe and tailored services, and racism. The Royal Commission into Victoria’s Mental Health System heard evidence that many Aboriginal people profoundly distrust mainstream health services due to their experiences of racism, lack of cultural safety and understanding, insensitivity to their cultural needs, and communication barriers. In a study of Aboriginal people in Victoria, nearly one-third of participants reported experiencing racism in health services in the previous year, including racist names, jokes or teasing, comments based on racial stereotypes, and being told they didn’t belong in Australia.¹⁵²

The Final Report of the Royal Commission into Victoria’s Mental Health System found that the system does not deliver safe, responsive or inclusive care for people from diverse communities in Victoria. The Commission made several recommendations to improve the cultural appropriateness of mental health services, as part of a shift to community-based, integrated and holistic care, including for people seeking care for alcohol use and mental ill-health. The Commission emphasised that responding to the needs of diverse communities, including in relation to language and communication, culture, gender and gender identity, and disability, should be core business for community-based services. Design and delivery of reforms should occur in partnership with LGBTIQ+ communities, culturally diverse communities, people with disability, and other diverse communities.

The Commission also made recommendations to ensure Aboriginal people experiencing alcohol or substance use or dependence receive more coordinated and integrated care and support. A key recommendation was for Aboriginal people to lead the design and delivery of Aboriginal social and emotional wellbeing initiatives and services, focused on providing holistic, healing-focused and culturally safe care. In addition, mainstream services should partner with Aboriginal community-controlled organisations to improve cultural safety and responsiveness.¹⁵³

The Victorian Government has commenced work on these reforms, and is developing a Diverse Communities Mental Health and Wellbeing Framework and a two-year Blueprint for Action, with the input of people from diverse communities, and community organisations. It has also invested in Aboriginal social and emotional wellbeing initiatives that provide culturally safe and respectful care in mainstream and Aboriginal-led settings.¹⁵⁴

There is a clear need for this work to address the provision of culturally appropriate treatment and support by integrated AOD and mental health services, and stand-alone AOD services. A focus of the Framework and Blueprint for Action should be ensuring these services are culturally responsive and safe for people from diverse communities. The Government should work closely with people from diverse communities with lived experience of alcohol harm to ensure services respond effectively to their needs.

Alcohol marketing and availability

The Advocates' experiences highlight the need for higher standards for alcohol marketing, and measures to address the availability of alcohol in Victoria.

Zelma would like to see controls on sponsored alcohol posts on social media, and the use of celebrity endorsements and influencers, which she believes are particularly influential for young people.

“Having young talent whose demographic is young people, I just don’t agree with. Because it’s basically your life they are targeting. You know who that content goes to.”

She is concerned that social media influencers, many of whom have underage followers, are used by alcohol companies to bypass controls on advertising to children and young people under the age of 18.

“As I understand it, liquor companies can’t advertise directly to under 18 users. But if someone under 18 is following, then the young person sees it.”

There is no government regulation of online marketing of alcohol in Australia. The limited controls that do exist are developed, implemented and overseen by alcohol companies themselves. However, research has found that this is ineffective, and cannot be enforced as it is not regulation.^{155, 156}

Higher standards for alcohol marketing, including independent, Government-led controls on targeted digital alcohol marketing, are needed to protect young people from alcohol marketing, and to help to address cultures of high-risk alcohol use.

There is also a need for more effective controls on the availability and supply of alcohol through Victoria’s liquor licensing scheme, such as stronger safeguards on online sales and home delivery of alcohol.

Theme 5: Embedding lived experience of alcohol harm in policy making

Joan is an experienced Lived Experience Advocate, and has been a key advocate in Victoria for including lived experience perspectives in family violence reform. She has a deep understanding of the importance and value of engaging people with lived experience of harm in the design and implementation of policy measures that affect them.

Joan described the need for meaningful, active engagement and collaboration between Lived Experience Advocates and policy makers. She believes this requires policy makers to ensure the voices of Lived Experience Advocates are heard and their expertise is respected. It also requires involvement of Lived Experience Advocates in co-design of policy measures and support services right from the start of the process, rather than seeking endorsement for approaches that have already been developed.

“We need to move away from being passive participants and ensure our voices are truly heard.”

Recognising the profound impact of family violence on children and young people, Joan highlighted the need to engage them and listen to their voices in co-designing policy responses and support systems.

“Whenever there’s the potential for young people and children to be affected, we have to have them in the room.”

Joan has advocated to the Victorian Government to ensure the perspectives of people with lived experience were meaningfully included throughout family violence policy development, service design, and decision-making processes. This led to a significant shift in Government towards more active and meaningful engagement of Lived Experience Advocates in co-design of family violence reforms.

“We really started to hammer home the point that we didn’t want to be just a tick box and we didn’t want to be consulted and be presented with something that was already cooked, like, ‘Here’s one we prepared earlier. Be happy with it.’”

“We really pressured government departments and elevated the message that we wanted to be involved right from the very start of any preparation or thought process that was leading towards policy development or changes being made. That we, the people that were to be affected by these policies and these changes, had to have a voice in the room, had to be listened to, had to be acknowledged. We saw a huge change.”

Emily also highlighted the importance of listening to the voices of people with lived experience, and creating platforms for them to be involved in co-design and co-production of policy and programs.

“Key decision-makers need to listen to and amplify lived and living experiences

meaningfully.”

“More often than not, people like me will get lost in a dataset. If we’re lucky, maybe we’ll be seen as a single quote in an article or we’ll have a tokenistic meeting with a government official. However, it’s often a fleeting and singular experience without any guarantee of genuine understanding or change.”

“There are so many people like me that are ready and willing to share our experiences. However, there are so few spaces for us to step into. Spaces need to be created for us to speak for ourselves and lead the changes that we know we need.”

Joan’s and Emily’s views are shared by all the Lived Experience Advocates in the Network. The Advocates believe strongly that people with lived experience of alcohol harm have a right to be recognised, respected and included in the decisions that affect them.

The Lived Experienced Advocates believe the same shift that has occurred in family violence and mental health is needed in the Government’s approach to policy development, program and service design, and decision-making on issues that influence alcohol harm. The Government should move from informing and delivering policies and services to people affected, to collaborating with these people through co-design and co-production. Formal spaces and mechanisms should be created to facilitate the input and engagement of Lived Experience Advocates. They should be engaged as active partners and experts in policy- and decision-making on the issues they understand deeply through real-world lived experience.

Policy recommendations

Drawing on the experiences and insights of the Lived Experience Advocates and work on including Lived Experience Advocates in mental health and family violence reform, the following recommendations are made to embed lived experience of alcohol harm in policy- and decision-making on alcohol in Victoria. The Lived Experience Advocates were consulted on, and endorse, these recommendations.

1. Alcohol lived experience strategy

The Lived Experience Network recommends that the Victorian Government should work with Lived Experienced Advocates to co-design and publish an Alcohol Lived Experience Strategy.

This should act as a guiding document to support the Victorian Government to establish and evolve the engagement of Lived Experienced Advocates in policy and program development relevant to alcohol use and harm.

It should outline the Government’s approach, phases of work and timelines for establishing structures, platforms and mechanisms to engage Lived Experience Advocates, and to expand their participation and involvement.

2. Alcohol lived experience advisory group

A Victorian alcohol lived experience advisory group should be established. The advisory group should comprise Lived Experience Advocates with diverse lived and living experiences of alcohol use and harm, from diverse communities in Victoria.

The advisory group should advise on strategies and frameworks for engaging people with lived experience in policy development and decision-making processes.

The advisory group should also be engaged as active partners, and play a central role, in co-design and co-production of the following:

- Victorian Government plans and strategies to reduce alcohol use and harm.
- Victorian laws and policies that influence alcohol use and harm.
- Victorian programs and awareness or education campaigns to address alcohol use and harm.
- Victorian services to support people affected by alcohol use and harm.
- Strategies to embed and build the capacity of people with lived experience in Victorian AOD and mental health workforces.
- A program of further Victorian research on lived experience of alcohol use and harm.

The engagement of the Alcohol Lived Experience Advisory Group should be meaningful, and should occur from the outset of these processes.

3. Alcohol lived experience engagement framework

An initial focus of the Alcohol Lived Experience Advisory Group should be to work in partnership with the Victorian Government to co-design and co-produce a framework for engaging Lived Experience Advocates.

The framework should set out a clear vision and objectives for including and engaging Lived Experience Advocates in alcohol policy development, program and service design, and decision-making. It should also establish the principles and values of this engagement, which may include empowerment, co-design, co-production, respect, diversity, inclusion, self-determination, dignity, authenticity and accountability.

The framework should consider barriers to engagement of Lived Experience Advocates, and propose solutions to enable and facilitate their participation. These may include:

- Providing a safe space or platform for engagement.
- Re-balancing power to ensure Lived Experience Advocates feel free to contribute and are not intimidated.
- Using plain and inclusive language.
- Providing a flexible approach that addresses individual needs of Lived Experience Advocates, including access and communication needs.
- Providing trigger warnings and briefings before meetings or engagement, and debriefs after.
- Connecting Lived Experience Advocates with appropriate support.

The framework should establish an expectation that the objectives, scope, roles, responsibilities and expectations of any engagement with Lived Experience Advocates will be clearly outlined. This should include providing details of training and development that will be provided to Lived Experience Advocates to help build

their capacity, and of any remuneration or reimbursement that will be provided to Lived Experience Advocates to recognise or compensate them for their participation, work, and out-of-pocket expenses.

In addition, the framework should outline processes and practices that will be followed, covering issues such as informed consent, language, confidentiality, dispute resolution, feedback and evaluation, and setting out models and tools that will be used to facilitate and support engagement.

4. Alcohol lived experience in policy and program development

The Network recommends that Lived Experience Advocates should be engaged from the outset and throughout the design, development, implementation and evaluation of policies and programs that influence alcohol harm, as part of active and meaningful co-design and co-production approaches.

The engagement of Lived Experience Advocates must consider the intersection between alcohol and mental health, family violence, education, youth and criminal justice in policy and program development, and recognise that a broad range of policies and programs influence the level and type of alcohol harm experienced in our communities. The voices of Lived Experience Advocates should be included, not only in alcohol law and policy development, but also in other relevant policy areas that influence alcohol use and harm.

The Network strongly recommends that reducing high risk alcohol use should be a focus area of the next four-year strategy under the *Public Health and Wellbeing Act 2008* (Vic). Lived Experience Advocates should be engaged in co-designing evidence-based policies to reduce alcohol harm in Victoria, including population-level policies to address harms from alcohol marketing, availability, and online sales and delivery.

In addition, there is a need for targeted programs and campaigns to increase community awareness of the risks and harms of alcohol use, to raise awareness and understanding of FASD, and to highlight the lived experiences of people affected. Programs and campaigns should aim to address cultures across the community that normalise alcohol use, to reduce stigma for people affected by alcohol use and harm, and to raise awareness of support available.

Lived Experience Advocates should be engaged as active partners in co-design and co-production of programs and campaigns, including by contributing to the development and dissemination of educational materials. They should also have the opportunity to share their stories to raise awareness and reduce stigma.

The Victorian Government should establish a feedback mechanism to allow people with lived experience to provide input on the effectiveness of alcohol programs, policies and support services. Regular surveys, focus groups, or consultations should be conducted to provide opportunities for feedback and recommendations for improvement.

5. Alcohol lived experience research

The Victorian Government should fund a program of research on lived experiences of alcohol harm in Victorian communities. The valuable real-world insights of the Lived Experience Advocates demonstrate the importance of this research. Further research is needed to build a deeper and more nuanced understanding of how people in Victorian communities are affected by alcohol use and harm, and to provide a stronger evidence base to inform laws, policy, programs and support services that respond to the needs of the people most harmed.

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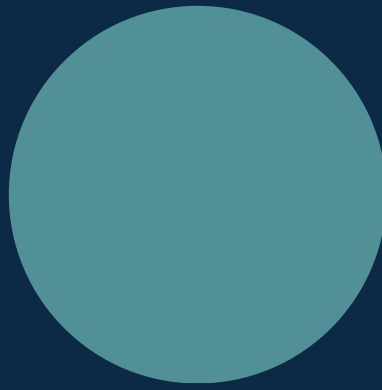
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