

Rapid Literature Review – Alcohol and Other Drugs Family and Carer Program Project

Report prepared for the Centre for Alcohol and Other Drugs, NSW Ministry of Health

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Our consultancy assists health and human service organisations find innovative and actionable solutions to complex situations.

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1. Introduction

1.1 Purpose of the project

The Centre for Alcohol and Other Drugs (CAOD), NSW Ministry for Health is seeking to design a model for delivering an Alcohol and Other Drugs (AOD) Family and Carers Program. The Program will be evidence-informed, appropriate and culturally safe and have a statewide reach.

The model will be informed by the <u>NSW Family and Carer Mental Health Program</u> (F&CMHP) and adapted to support family and friends of people who use alcohol and other drugs. The F&CMHP is a partnership approach between local health districts (LHDs) and the Justice Health and Forensic Mental Health Network (JH&FMHN), Community Managed Organisations (CMOs) and the Mental Health Branch, Ministry of Health. CAOD has commissioned Avertis Consulting to lead the project.

1.2 The rapid review

CAOD would like to understand the most important elements and interventions to include in a family and carer program to improve the wellbeing and health outcomes of families and carers, and the people they support. One component of the project is an evidence review/appraisal to identify existing family and carer support programs, services and tools to map out common elements conducive to success. The review will inform design of the model and requirements of the program.

Aims

Key areas of interest for the review include:

- evidence-based models and their key elements (e.g. treatment principles, model of care, workforce, etc) to support family and carers of people who use AOD to improve their health and wellbeing
- other programs, services, interventions and tools to support family and carers of people who use AOD
- key elements of services, key structures for service delivery and key partnerships to work with families and of those at risk of experiencing harm from AOD
- desired/required outcomes of programs, services, interventions and tools that support family and carers of people who use AOD.

Scope

The review aims to identify outcomes, and 'key principles' or 'key elements' that may be included in a model of care. It focuses on family and carer programs and does not cover treatment or support programs solely for those who use AOD or programs for the children of people who use AOD. The overall project will not deliver detailed models of care for implementation or operational guidance. It will not develop costings to inform commissioning of services but will provide information that may inform resource allocation.

1.3 Policy and funding context

The NSW Government is committed to supporting individuals, their families, and communities impacted by alcohol and other drug use (AOD), which cause immense health, social, and economic harm to users, their families, and the community. The Special Commission of Inquiry into the Drug 'Ice' (the Inquiry) recommended "That NSW Health develop and implement a comprehensive strategy to better meet the needs of families and carers impacted by the use of amphetamine-type stimulants, which includes: a program similar to the NSW Family and Carer Mental Health Program, adapted to support family and carers of people who use amphetamine-type stimulants." (Howard, 2020, Vol 3, p. 768).

In its response to the Inquiry, the NSW Government supported this recommendation stating, "NSW Health is committed to a comprehensive approach to meeting the needs of family and friends impacted by the use of ATS, including: New funding of \$3 million annually to support the establishment of a new dedicated AOD family and carer program, to be delivered as a partnership between health districts and non-government organisations, addressing significant unmet support needs for families and carers." (NSW Government, September 2022 p.87).

The project will need to identify the priority components for the new AOD Family and Carers program model as funding is not unlimited. This review will assist in deciding how to best target resources to evidence based and evidence informed approaches that are acceptable to the community.

1.4 Rationale for supporting family and carers

The impact of harms associated with a person's use of AOD can extend beyond the use itself. Partners, children, members of the broader family and friends may be significantly affected by a person's AOD use and may experience complex issues and interacting risk factors.

While not all people who use AOD will harm those around them, there is, for example, a strong association between the use of crystal methamphetamine and domestic and family violence and the abuse and neglect of children and young people. Other effects include stress and anxiety, mental health issues, stigma and discrimination, providing additional financial support/debt support, providing food and accommodation, attending appointments, additional caring responsibilities for children and financial hardship (Howard, 2020, see vol. 3).

Families and carers are often ill-equipped to deal with the physical and mental health care needs of those who use AOD, as well as their own needs. It is recognised that supporting families to develop the resilience, skills and capacities they need to support their relative results in better outcomes for both the person using AOD, their children and their whole family.

Policy and service responses in NSW are poorly equipped to deal with the effects of AOD use on family and friends. There is a lack of access to and services for both people who use AOD and their families, especially in rural and remote areas of NSW. Families and carers may find it difficult to navigate the healthcare system, there is a lack of drug treatment services and mental health services, and there are often long waiting times for their loved ones to enter treatment.

There is a need for support services specifically for families and friends, for example, to provide: accurate information about AOD; opportunities to meet with others in the same situation; help in developing coping skills; and emotional and practical support to help a loved one navigate the system. It is important to support family members and carers for their own wellbeing as well as for the benefits that accrue to those they care for – people with AOD use, their children and the whole family.

1.5 Terminology

The Inquiry report (Howard, 2020, vol.3, p. 754) used the term 'family and friends' to refer to those people close to the person using ATS (amphetamine type stimulant), including intimate partners, parents, grandparents, siblings, children, aunts and uncles. It also encompassed non-biological 'chosen' family and friends of the person using ATS and extended kinship and family relationships.

An inclusive definition of family is important for many groups, including the LGBTQI+ community, where nonbiological chosen family can be particularly important, and the Aboriginal community, where kinship and family structures may extend beyond the nuclear family structure. The reference to 'parents' encompasses the range of people who may have a role caring for a child or young person. This includes people who have a biological or other type of relationship with the child or young person, such as a legal guardian.

Throughout this report, we have used the term 'family and carers' to refer to the above groups, carers, friends and significant others but have reported on specific groups where relevant and identified in the literature.

Within NSW Health, the term 'Aboriginal' is generally used in preference to 'Aboriginal and Torres Strait Islander', in recognition that Aboriginal people are the original inhabitants of NSW¹. For the most part in the report, the word 'Aboriginal' is used to encompass Aboriginal and Torres Strait Islander people, except where there is broader representation used in the research.

Specific drug type is only referred to in the context of a particular report or research, otherwise the broad term, alcohol and other drugs (AOD), is used throughout, aligned with the overall project scope to design an AOD Family and Carers Program.

¹ https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/GL2019_008.pdf

2. Review approach

2.1 Method

The Rapid Review followed the general process as outlined in the VCU Research Guides Rapid Review Protocol² and drew from the Cochrane Handbook for Systematic Reviews of Interventions.³ Given the nature of the questions and the broad type of information sourced, evidence quality grading was not used however the scope of information, author and source provide a guide to the relevance and quality of reporting.

2.2 Key questions

The review has two main focus areas – the desired outcomes for families and carers, and the models, services and programs that are likely to deliver those outcomes. The five questions investigated that are aligned with these focus areas are identified below.

Focus Area 1 - Outcomes

- 1. What are the desired/required health and wellbeing outcomes of programs, services, interventions and tools that support family and carers of people who use AOD?
- 2. What supports and service structures are required to improve the health and wellbeing outcomes of both the family and carers of people who use AOD?

Focus Area 2 – Models

- 3. What evidence-based models and their key elements (e.g. treatment principles, model of care, workforce etc) exist that support family and carers of people who use AOD to improve the health outcomes of both families and carers and AOD patients?
- 4. What other (not evidence-based) support programs, services, Interventions and tools exist for family & carers of people who use AOD?
- 5. What are the key elements of these models, programs and services e.g. treatment principles, model of care, key structures, key partnerships, workforce staff and skills?

2.3 Search strategy and outcomes

2.3.1 Primary document search

A document search was performed by the NSW Ministry of Health Library in May 2023 with the following terms and databases:

Google

Search Med, EmB, EmC, Psyc, JBI

(drug or alcohol or substance or ice or meth or methamphetamine or opioids or opiates or marijuana or cocaine or amphetamine).tw. AND (addiction or treatment or detox* or programs or models of care or tools or resources).tw. AND (family or parent or friend or carer or support person or guardian or social support).tw. AND ((Patient Reported Outcome Measures/ or Patient Outcome Assessment/ or Outcome Assessment, Health Care/) OR (wellbeing or impact on carers or carer impact or Health-related quality of life or carer burden).tw.)

Embase <1996 to 2023 May 23>

Emcare Nursing & Allied Health Database <1995-current>

JBI EBP Database <Current to May 17, 2023>

MEDLINE(R) All including Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions(R) <1946current>

APA PsycInfo <2002 to May Week 3 2023>

² <u>https://guides.library.vcu.edu/rapidreview</u>

³ https://training.cochrane.org/handbook/current

1. ((drug or alcohol or substance or ice or meth or methamphetamine or opioids or opiates or marijuana or cocaine or amphetamine) and (addiction or treatment or detox* or programs or models of care or tools or resources) and (family or parent or friend or carer or support person or guardian or social support)).tw. and (Patient Reported Outcome Measures/ or Patient Outcome Assessment/ or Outcome Assessment, Health Care/ or (wellbeing or impact on carers or carer impact or Health-related quality of life or carer burden).tw.)

2862

2. remove duplicates from 1 - 2129

3. limit 2 to yr="2015" 111

4. limit 3 to english 109

Search PubMed

((care giver burden[MeSH Major Topic]) OR ("burden of care"[Title/Abstract])) AND (addiction[Title/Abstract] OR substance abuse[Title/Abstract] OR alcohol*[Title/Abstract] OR drug[Title/Abstract]);

Total records - 60;

filtered by date 2015-current - 40;

filtered by language - English - 38

((("support for") AND (family[Title/Abstract] OR parent[Title/Abstract] OR friend[Title/Abstract] OR carer[Title/Abstract] OR support person[Title/Abstract] OR guardian[Title/Abstract] OR social support[Title/Abstract])) AND (drug[Title/Abstract] OR alcohol[Title/Abstract] OR substance[Title/Abstract] OR ice[Title/Abstract] OR meth[Title/Abstract] OR methamphetamine[Title/Abstract] OR opioids[Title/Abstract] OR opiates[Title/Abstract] OR marijuana[Title/Abstract] OR cocaine[Title/Abstract] OR amphetamine[Title/Abstract] OR opiates[Title/Abstract] OR marijuana[Title/Abstract] OR cocaine[Title/Abstract] OR detox*[Title/Abstract] OR programs[Title/Abstract] OR models of care[Title/Abstract] OR tools[Title/Abstract] OR cools[Title/Abstract] OR methamphetamine[Title/Abstract] OR cocaine[Title/Abstract] OR detox*[Title/Abstract] OR programs[Title/Abstract] OR models of care[Title/Abstract] OR tools[Title/Abstract] OR tools[Title/Abstract]

Total records - 527;

filtered by date 2015-current 2015 - 267;

filtered by language - Engl. - 265.

Search AcSCom, BusSCom, HealthBusE

AB (family or parent or friend or caregiver or support person or guardian or social support) AND AB (caregiver burden or burden of care) AND AB (addiction or treatment or detox* or program) AND (drug or alcohol or substance abuse)

Total records - 1,165

filtered by date 2015-current - 735

filtered by language - English - 718

The searches yielded 49 citations and two reports whose abstracts were reviewed manually. Twenty-three of these abstracts/reports were included in the Review. Twenty-eight citations were excluded, primarily because they did not involve studies related to treatment or outcomes for family and carers of people who use AOD.

2.3.2 Additional document search

An additional document search was conducted on sites further to discussions with the project team and sourced from key article references. This search yielded 35 additional documents.

2.3.3 Search outcomes

58 documents were initially included in the Review. Analysis of the content resulted in a final total of 47 documents used in the Review. Most research papers did not have high levels of evidence (as defined by protocols such as the NH&MRC Evidence Hierarchy). Some papers were general reviews, reports, frameworks or policy documents. These papers were considered relevant for the purposes of the Review. In addition, information was sourced from jurisdictional websites. Examples of some key services are provided, however the review does not provide an exhaustive list of the services, programs and supports that may be available. Inclusions are presented to inform the design of the Family and Carer Program model.

3. Key findings

This section provides an easy-to-find summary of the key findings that are detailed, along with key references, in Section 4 and 5 of the report.

The review focuses on models of services and supports found to improve outcomes for families and carers of people using AOD. This will largely be through building the resilience, skills and capacities of family members and carers required to maintain their own wellbeing as well as to support their loved ones.

The individuals that family and carers support often include the person using AOD, their children as well as broader family members. The literature shows that improving outcomes for families and carers is linked to improved recovery outcomes for people using AOD and the broader family group.

Family and carers who access support for themselves are more likely to maintain their own wellbeing and their support-giving role.

3.1 Focus Area 1: Outcomes

It is important to understand the impact of AOD use on family and carers, and their needs, in order to identify relevant outcomes and the models of services or supports required to achieve those outcomes.

The role of family and carers

The supports that family and carers often provide include:

- financial and debt support
- food and accommodation
- transport to appointments
- care and practical support for their children
- maintaining connection to culture (for Aboriginal people)
- other practical and emotional support.

They often provide these supports in the context of managing their loved one's challenging behaviours, disruption to their own employment and routines, reduced income, and their own physical and mental health needs. Family and carers are also frequently caring for children of the person using AOD and trying to mediate the impacts of the person's AOD use on the children.

The needs of children impacted by parental AOD use

Research has found that children of parents using AOD often have compromised physical and psychological support from their parents, and an increased likelihood of developing emotional and behavioural issues. Although the AOD Family and Carer's project will not be designing a program to meet the needs of children, they are considered in the broader context of outcomes for family, carers and people using AOD.

The impacts on family and carers

Table 1 summarises some of the key impacts of a person's AOD use on families and carers.

Table 1: Impacts of AOD use on family and carers

Impacts of AOD use on family and carers					
• Financial problems and intimidation with unpaid debts	• Stigma, shame and guilt, racism				
• Increased conflicts in family relationships, with greater potential for domestic and family violence	 Increased caring burden when providing for the needs of children 				
 Increased mental health symptoms such as anxiety, trauma, post-traumatic stress, and depression 	Isolation and inadequate emotional support				
Declining physical wellbeing	Sense of hopelessness				

Barriers to family and carers accessing information, services and supports

Family members and carers have limited access to the information, services and supports they want and need to help them while they are caring for a person using AOD. Family and carers report being excluded from involvement in their loved one's treatment and missing out on essential information about care planning. They felt this limited their capacity to assist in their loved one's recovery. They attributed this exclusion to system-level barriers (policy, funding models, fragmented and siloed approaches to care) and non-inclusive practices by services and individual clinicians.

They also identified other barriers to being able to access information and supports such as counselling services, support groups, websites and referral pathways. Table 2 outlines some of the barriers identified in the literature.

The very limited availability of culturally appropriate and responsive information and supports, means Aboriginal people and people from Culturally and Linguistically Diverse (CALD) backgrounds were at an even greater disadvantage.

Table 2: Common service and support access barriers for family and carers

Barriers to access

- Policy and funding models that do not support engagement with family and carers
- Fragmented approaches to care, with services operating in silos and operating from different ideologies which limits information and support to family members
- Geographical accessibility, particularly for people in rural and remote areas
- Limited access to culturally safe and responsive services for Aboriginal people
- Limited relatable and accessible information (poorly translated) and culturally appropriate supports for CALD communities
- Being undervalued as an affected family member
- Limited health literacy related to AOD use (knowledge, communication skills)
- Poor awareness of existing services
- Poorly designed websites that are not user friendly
- Cost of services
- Long wait times for appointments
- Older carers (65 years and over) are less likely to connect with other carers

Outcomes

Improved supports to family and carers have been shown to improve outcomes for people using AOD and their children. Outcomes for people using AOD include improved treatment retention, increased rates of abstinence, reduced substance use, improved mental health symptoms and improved overall quality of life. For those engaged in parenting and relationship based interventions, it also improved parenting skills, family functioning, family and social relationships and physical and psychosocial outcomes for children.

An Outcomes Framework for information and support services working with family and friends impacted by alcohol and other drug use recently published by the Alcohol and Drug Foundation (Appendix I) identifies the broad outcome areas for targeting by AOD family and carer programs and services.

Five outcome dimensions seek to address both the impacts (e.g. mental health issues, financial problems, isolation, family relationship stresses etc.) and barriers (e.g. stigma, lack of awareness, inaccessibility, non-family friendly approaches to care etc.) identified in the literature for families and friends.

The five outcome dimensions are:

- Reduced Stigma
- Increased Awareness
- Skill Acquisition
- Better Accessibility
- Quality Improvement.

3.2 Focus Area 2: Models

Critical components of the models of services and supports for families and carers identified in the peer reviewed and grey literature that have been shown to improve outcomes include:

- Policies and strategies and funding allocation that support AOD services to embed a family-focused approach as part of business-as-usual care
- Core principles and components of any information, support or program to be non-stigmatising, nonjudgmental, person-centred, recovery-oriented, equitable and accessible, evidence-informed, culturally responsive, holistic and coordinated
- Readily accessible information about AOD use and ways for family and carers to support themselves that consider literacy levels and preferred communication modes including reference material such as handbooks, manuals, toolkits and online information, fact sheets, websites and resources
- Readily available and accessible supports such as free, confidential 24/7 helplines, phone and web-based based referral services and supports
- Peer support/mutual aid with others who have had similar experiences
- Clinician led/facilitated group sessions and manualised programs (provides expert input and supports program fidelity)
- Access to interventions that are designed to increase social support (e.g. peer support groups), decrease burden, address mental health concerns, coping and problem solving
- Case management supports for issues such as financial, housing, etc.
- Referral pathways for the family and carers as well as options for the person using AOD
- Different modes of delivery online, face-to-face, individual, group so family and carers can choose what best suits their needs
- Workforce models that support inclusion, reduce stigma, improve cultural safety and improve access such as involvement of Aboriginal staff members, consumer peer workers and staff with lived experience of caring for someone with AOD
- Involvement of family and carers in design and delivery of services and supports at the local level and at the system level through carer peaks or individual representation on statewide committees.

4. Findings: Focus Area 1 - Outcomes

This section presents findings from the literature and findings from recent AOD inquiries related to outcomes. Information is presented separately, but the findings are the same.

Focus Area 1 - Outcomes

- 1. What are the desired/required health and wellbeing outcomes of programs, services, interventions and tools that support family and carers of people who use AOD?
- 2. What supports and service structures are required to improve the health and wellbeing outcomes of both the family and carers of people who use AOD?

4.1 Needs of family and carers

It is important to understand the impact on and needs of family and carers of people who use AOD to address what are relevant outcomes and what services or supports are required to achieve those outcomes.

4.1.1 Social, emotional, physical and mental health and financial impacts

Recent AOD literature has summarised research on impacts of AOD use on family and carers (e.g. Kane, Snethen, Gwon, & Oh, 2023), including social, emotional, physical and financial impacts. Addressing the needs of family and carers may depend on their specific circumstances, and the different types of AOD use may require different types of responses. Some examples are provided below.

A Turkish qualitative study examining the burden of care on caregivers of relatives with AOD found that caregivers had financial problems, increased conflicts in relations with their families and their immediate surroundings, and breakdown in their wellbeing (Uluyol & Bademli, 2020). When the caregivers were asked about their needs in AOD treatment, financial support ranked first. For some, loss of time in the workforce due to caring responsibilities reduced their income and negatively affected the quality of life of families.

Soares et al. investigated the burden of care associated with informal caregivers of those using AOD (Soares, Ferreira, & Graça Pereira, 2016). They found that caregivers would benefit from interventions that increased social support, and decreased burden, depression and distress, particularly for those who have other care responsibilities. They also suggested that health professionals may benefit from having training in family oriented AOD treatments in order to better recognise burden and promote biopsychosocial interventions for the caregivers.

Russell et al. investigated factors that predict caregiving burden among family caregivers of individuals seeking treatment for AOD use (Russell, D'Aniello, Tambling, & Horton, 2022). Their results indicated concerning levels of mental health symptoms and relationship strains in these families. They suggested that providing stress reduction and emotion regulation intervention for highly stigmatised families is not only critical for improving mental health outcomes but could be important for long-term family recovery by promoting adaptive relationship dynamics essential to building resilience to enduring stresses. Improving awareness of, and access to these interventions has the potential to bolster positive outcomes for caregivers and those using AOD.

In 2020, the Alcohol and Drug Foundation (ADF) conducted a nationally representative survey of 510 adults who were concerned about a family member or friend's AOD use. More than 70 per cent of respondents who needed relevant information and support reported they did not immediately seek help, with more than a third of respondents only seeking support when their family member or friend was perceived to be of high risk (cited in Skinner, Duraisingam, & Fischer, 2021). In a recent study of 90 affected family members, over three-quarters of participants had not received any assistance from AOD services (McCann, Stephenson, & Lubman, 2021). McCann et al. (2021) concluded that services and AOD clinicians should target, but not be restricted to, reducing stress and strengthening the physical and mental wellbeing, and hopefulness of family and carers.

The 2022 Carer Wellbeing Survey⁴ (Schirmer, Mylek, & Miranti, 2022) reports on the wellbeing and health of Australian carers. It shows that carers continue to be at very high risk of poor wellbeing and health, compared to others in Australia. Carers were less likely to report having good access to information from medical professionals if they were younger, were Aboriginal or Torres Strait Islander, usually spoke a language other than English at home,

⁴ "A carer is a person who looks after someone who has a disability, mental illness, drug or alcohol dependency, chronic condition, dementia, terminal or serious illness; or who is frail or needs care due to ageing. They do this not as their paid job, but as a family member or friend. The Carer Wellbeing Survey focuses on those carers for whom caring represents a significant part of their day-to-day life – typically at least 10-15 hours per week, and often much more than this."

were not the person's primary carer, cared for the person episodically, cared for a person with mental illness or psychosocial disability, and/or cared for a person with AOD dependency. Carers of people who use AOD were among groups who were more likely to connect with other carers to share experiences and knowledge but less so if they were older carers aged 65 years and over.

4.1.2 Stigma, shame, guilt and Isolation

McCann et al. (2021) described three dimensions of stigma many family and carers may experience which can exacerbate psychological and other harms:

- public stigma negative attitudes of the public towards people with a 'reprehensible' characteristic [e.g., AOD misuse]
- self-stigma internalisation of public stigma and consequential lowered self-efficacy and self-esteem
- 'courtesy' stigma families experience shame and blame resulting from their relative's AOD misuse, increasing their social isolation from others (McCann et al., 2021).

Family members affected by another's AOD use represent a large population at risk for reduced social support. As part of a larger mixed methods study, Kane et al. (2023) used qualitative inquiry to explore the experiences and perceptions of social support of family members affected by a person's AOD use. The themes that emerged were somewhat related to those described by McCann above, feeling alone and unsupported: "*We are all alone, and we have to fend for ourselves; No one understands what we are going through; People cannot relate and recoil from us*" (Kane et al., 2023, p.592). Education was perceived as lacking among their support systems of family and friends. At times, family members resisted the help of others due to a fear of negative responses, which led to them having inadequate emotional support. Stigma, shame, and humiliation were feelings shared by the family members, which caused them to engage in secrecy and minimise contact with others, reinforcing their social isolation (Kane et al., 2023).

4.1.3 Impacts on children

There is a large body of evidence that children can be severely affected by a parent's use of AOD. It is important to note that poor parenting is not an inevitable outcome of AOD use, however, AOD use can compromise a parent's ability to provide psychological and physical support to their children. There is evidence that children whose parents use AOD are more likely to develop emotional and behavioural issues (Commonwealth of Australia & Cabinet, 2015).

The problems children face are not only related to the AOD use itself, but also to other family problems which commonly co-exist, particularly domestic violence/abuse and parental mental health problems (Templeton, 2010). How children will be affected, or not, is influenced by a range of variables and risk factors (e.g. gender, age, ethnicity, whether the person using AOD is a parent or sibling, the extent of the AOD use, length of exposure, whether there is more than one person using AOD in the family, impacts on daily life, other problems, etc.). It has been assumed that if adult family members are demonstrating benefits through receipt of an intervention (e.g. healthier, coping better), then other family members, including children, can also benefit (Templeton, 2010).

Some issues children have identified as crucial to them in receiving support because of familial AOD use include: issues of confidentiality, worry that they will be removed from their families, feeling guilty for getting help or that they are betraying their families, wanting to be listened to, wanting practical help or physical protection and wanting to meet other children in similar circumstances (Templeton, 2010).

4.1.4 Impacts on Aboriginal families

Appreciating the interconnectedness of family kinships is important for Aboriginal people, especially as families are often the first line of support to people who use methamphetamine in a situation of limited, inaccessible or inappropriate services. Gendera et al. (2022) found Aboriginal and Torres Strait Islander families play a central and under-recognised role in the support of people who use methamphetamine and in reduction of drug-related harms. The care provided by families encompassed: practical, material, financial and wellbeing support; help to access health and emergency services; social care, such as looking after grandchildren or support post rehabilitation; and lastly, maintaining a connection to culture. Often families provided support without external (professional or informal) help due to a lack of appropriate services, stigma and racism attached to accessing services for this population, and limited knowledge about how to seek help. Most study participants underlined the essential role of family in supporting people who use, however family can also present a risk factor, where young people grow up in a social environment favourable towards drug use.

Gendera et al. (2022) studied the support needs of Aboriginal and Torres Strait Islander family members of individuals using methamphetamine by conducting focus groups and interviews with mostly Aboriginal community, family members and service providers (147 participants) (Gendera et al., 2022). They applied a social and emotional wellbeing framework (Gee, Dudgeon, Schultz, Hart, & Kelly, 2014) to examine the support needs and role of family in mitigating methamphetamine-related harms. Methamphetamine and other drug use among Aboriginal and Torres Strait Islander people has been linked to historic and structural disadvantages, including the intergenerational impact of colonisation, racist policies and poverty. These disadvantages reinforce and compound one another while limiting the access to health care, such as comprehensive primary care.

4.2 Barriers to family and carers accessing services and supports

4.2.1 General barriers

Skinner et al. (2021) summarised the literature on a range of barriers and challenges that family and carers may experience when seeking access to information and support. Common barriers included:

- Stigma, shame and guilt
- Privacy concerns
- Limited health literacy (knowledge, communication skills) related to AOD use
- Lack of awareness of existing services
- Poorly designed websites (i.e., not user friendly)
- Long wait times for appointments
- Cost of services
- Language barriers and lack of general health literacy
- Culturally inappropriate, unrelatable and poorly translated information and support for CALD and Aboriginal and Torres Strait Islander communities.

Other practical constraints include available time, child-care, and geographical accessibility or financial costs (Wilson, Rodda, Lubman, Manning, & Yap, 2017).

In their qualitative study, McCann and Lubman found that family members experienced several overlapping and at times competing help-seeking obstacles and enablers in accessing informal and formal support for themselves and on behalf of their relative with AOD misuse (McCann & Lubman, 2018). They identified stigma, feelings of hopelessness, being undervalued as an 'affected family member' and negative experiences of previous AOD service discouraged help-seeking. Three help-seeking facilitators were identified: previous positive help-seeking experiences; overcoming shame and isolation and being open with trusted significant others; and, persevering in help-seeking.

4.2.2 System-level barriers

A study on gambling services and supports in New Zealand (Palmer Du Preez et al., 2022), identified policy and funding models as a key barrier as participants believed they were not supportive of service engagement with family and carers. Additional barriers included low practitioner confidence and competence working with families. Family mistrust of services related to social stigma was identified as a powerful barrier to service engagement. Additional barriers included service design around individual gamblers and low cultural awareness and competency (e.g. lack of appropriate space for large families to gather, lack of diversity in the workforce).

Schnute (2017) presented work on in-depth interview and focus groups of family members experience of their participation in addiction care and care transitions in the wider context of their own support needs and care and life goals (Schnute, 2017). Accounts by family members highlighted systemic and service level barriers to integration which were not only based on different funding mechanisms and organisational capacities, but also on fragmented care systems and ideological differences. They noted underexplored pathways among addiction services, primary care, and mental health and social services, leading to support overlaps and collaboration gaps. A key conclusion was that professional perspectives about family and carers can be one-sided with an emphasis on the family member in a care-participant role and professional support can be limited to illness-specific interventions or focus on a specific setting (e.g. inpatient treatment), or pathway element (e.g. treatment uptake), leaving family members with limited information and support.

There is also a lack of clear pathways in providing family and friends the support and guidance they require for their particular needs (Kourgiantakis, Ashcroft, Mohamud, Fearing, & Sanders, 2021).

4.3 AOD inquiry findings about family and carers

4.3.1 Australian inquiries

Findings

The National Ice Taskforce had a strong focus on families and their needs and reported on the harms of drug use, not only on the user but their friends, family and community (Commonwealth of Australia & Cabinet, 2015).

Evidence to the NSW Special Commission of Inquiry into the Drug 'Ice' described how the use of drugs can have profound impacts on the families and carers of the person using AOD. These can include chronic and/or post-traumatic stress, severe anxiety, trauma and social isolation and negative impacts on physical, emotional, social and economic wellbeing as well as intimidation because of unpaid drug debts (Howard, 2020).

Policy and service responses in NSW were described as ill-equipped to deal with the effects of AOD use on family and carers. There is a lack of services for both people who use AOD and their families, especially in rural and remote areas of NSW. The evidence pointed to the need for state-wide, holistic, wraparound services to better meet the needs of those affected by AOD use (Howard, 2020 vol.3).

Recommendations

Among the recommendations of the National Ice Taskforce was improving access to online interventions to access support and information. The NSW Inquiry went further and recommended "That NSW Health develop and implement a comprehensive strategy to better meet the needs of families and friends impacted by the use of amphetamine-type stimulants (ATS), which includes: a program similar to the NSW Family and Carer Mental Health Program, adapted to support family and friends of people who use amphetamine-type stimulants.".

The NSW Inquiry heard there were insufficient support services in NSW designed to meet the needs of families, and a lack of comprehensive information about what support is available and how to access it. While there were examples of good practice in NSW, there should be a state-wide approach that facilitates comprehensive access to appropriate services for families and friends affected by their family member's use of drugs.

In its response to the Inquiry, the NSW Government supported this recommendation with funding of \$3 million annually to support the establishment of a new dedicated AOD family and carer program, to be delivered as a partnership between health districts and non-government organisations, addressing significant unmet support needs for families and carers.

4.3.2 New Zealand inquiry

Findings

The report on the New Zealand Government inquiry into mental health and addiction (Patterson, Durie, Disley, & Tiatia-Seath, 2018) found similar concerns. Many families and whānau⁵ reported on the lack of services to support their own wellbeing during particularly difficult times when caring for a loved one. Many felt that supporting their family member came at a high cost to their own mental and physical health and they felt isolated and experienced anxiety or depression themselves. Some family and whānau may also be struggling with their own complex challenges such as addictions, mental health problems, financial stress, discrimination, housing difficulties and other social determinants that were compounding stressors.

Although some families and whānau found support networks and professional services in their community, limited support and respite options were available and not all families could afford them. This difficulty was exacerbated when a family member had complex needs, multiple challenges, chronic physical conditions or no agreed diagnosis. Not knowing where to go and the services available for support compounded the situation.

Recommendations

The New Zealand Inquiry recommended a review of the support provided to families and whānau of people with mental health and addiction needs and proposals to fill identified gaps for supports that enhance access, affordability and options for families and whanau.

⁵ Whānau is the Māori language word for the basic extended family group, encompasses three or four generations.

4.4 Outcomes for people who use AOD

Evidence suggests that treatment of AOD use without the appropriate involvement and participation of family members may hinder treatment success and recovery. Supporting relatives and other family members in their own right can also indirectly benefit the whole family, such as children or the relative, e.g. by improving engagement, retention and outcomes in AOD treatment (Whittaker, Templeton, Mitchell, & Neilson, 2014).

Research and submissions to the NSW Inquiry indicated that family and carers play an essential role in treatment, improving outcomes and maintaining recovery. Quality relationships with informal supports were associated with higher rates of abstinence, both directly following treatment and in the longer term. Family involvement in specific AOD treatment were also shown to improve treatment retention, increase rates of abstinence, reduce substance use, improve mental health symptoms and improve overall quality of life (see Howard, 2020).

Family and carers of people who use AOD who are able to access support for themselves are more likely to maintain their support-giving role (McCann & Lubman, 2018). McCann et al. found that when help-seeking occurs, it is often of short duration and restricted to crisis circumstances (McCann et al., 2021). The NSW Inquiry noted that it is recognised that supporting families to develop the resilience, skills and capacities they need to support their relative results in better outcomes for both the person using AOD and their whole family.

The <u>NSW Health Clinician Care Standards: Alcohol and Other Drug Treatment</u> (NSW Health, 2020) note that development of these Standards is part of a broader aim to develop a mechanism to describe the quality and outcomes of treatment for clients who enter treatment for drug and or alcohol use. The Standards take a person-centred care approach which includes involving carers, family members and significant others. A key element under Standard 3 – Care planning is a care plan is developed in collaboration with the client and where relevant their carers/friends/family/and other service providers.

4.4.1 Outcomes Framework

The Alcohol and Drug Foundation (ADF) recently published <u>An Outcomes Framework for information and support</u> <u>services working with family and friends impacted by alcohol and other drug use</u> (Fischer et al., 2022). The Framework supports service providers in delivering information and/or other support to family and carers of people affected by AOD related use. The Outcomes Framework was developed by the National Centre for Education and Training on Addiction (NCETA) in collaboration with the ADF and multiple stakeholders across Australia. While the key purpose of the Outcomes Framework is to have a standard set of outcomes that can be systematically measured for evaluation and research purposes and allow for benchmarking and quality improvement initiatives, it also provides a helpful guide and focus to the development of services.

The overarching vision of the Outcomes Framework is to "realise improved health and social outcomes for family and friends affected by alcohol and other drug-related harm, facilitated by culturally safe and inclusive information and support services". The principles of information and support services, or 'treatment', for family and carers, are the same as they are for people who use AOD and people who no longer use AOD, i.e. person-centred, equitable and accessible, evidence-informed, culturally responsive, holistic and coordinated and non-judgement, non-stigmatising, non-discriminatory.

The Outcomes Framework provides a structured approach to establish how family and friends' information and support services perform in five key dimensions:

- Reduced Stigma
- Increased Awareness
- Skill Acquisition
- Better Accessibility
- Quality Improvement.

Each of these dimensions is evidenced by one defined outcome (five in total), which was informed by the consultations and prior work undertaken by the ADF and the sector. These outcomes are supported by 14 indicators that can be tracked over time – see Table A1 (Appendix I) (Fischer et al., 2022). In developing the Outcomes Framework the authors reported they did not identify any existing measures that reflected the same context of the framework (Skinner, Duraisingam, et al., 2021). They described some of the limitations of the literature and using other frameworks and assessment tools to determine the framework and indicators/measures. However, in the absence of this research, the Outcomes Framework is well informed by extensive consultation and over time it will be strengthened through its use and evaluation.

5. Findings: Focus Area 2 - Models

This section presents findings from the peer reviewed and grey literature about models, programs and service elements. Examples of each of the program types are included.

Focus Area 2 - Models

- 3. What evidence-based models and their key elements (e.g. treatment principles, model of care, workforce etc) exist that support family and carers of people who use AOD to improve the health outcomes of both families and carers and AOD patients?
- 4. What other (not evidence-based) support programs, services, Interventions and tools exist for family and carers of people who use AOD?
- 5. What are the key elements of these models, programs and services e.g. treatment principles, model of care, key structures, key partnerships, workforce staff and skills?

5.1 Overview of intervention types and approaches

5.1.1 Broad intervention types

The <u>NADA Tools for change toolkit</u> identified 12 broad interventions for working with families which summarises the type and intensity of support that may be provided (Network of Alcohol and other Drugs Agencies (NADA) Publications, 2009):

- considering families when working with a client (family focused practice)
- telephone support for families
- effective referral of families to other support services
- providing AOD and mental health information to families
- providing community education forums
- establishing support groups for families (facilitated)
- self-help groups (peer support/mutual aid)
- telephone counselling
- single session therapy
- counselling to families individual and joint
- support for family members whose relative is not a client of the service
- networking and liaising with other family focused organisations including mental health services.

5.1.2 Cultural considerations

Krakouer et al (2022) conducted a systematic review of community-based models of AOD support for Aboriginal and Torres Strait people in Australia (Krakouer, Savaglio, Taylor, & Skouteris, 2022). Seventeen studies were included in their review. While most of the studies were focused on reducing AOD use, they did find that acceptable components included cultural safety which was composed of inclusion of family and kin, Aboriginal AOD workers, outreach and group support. They also note the importance of holistic, integrated and strengths-based approaches ensuring that programs can address the impact of the broader societal environment (i.e. racism, oppression, marginalisation and discrimination) which impacts substance use.

Gendera et al. (2021) made specific suggestions to support Aboriginal and Torres Strait Islander families:

- tailored resources (websites and phone helpline for supporters)
- professional services (primary health working in collaboration with local knowledge, counselling and outreach support)
- grassroots approaches that foster connection to community, mutual support and cultural connection (Aboriginal run art or cultural programs, peer groups, individual and group mentoring to break social isolation and stigma)
- addressing the economic and historic determinants that shape Aboriginal livelihoods (racism and lack of opportunities)
- initiatives to engender greater community cohesion and cultural connection for individuals, families and communities.

5.2 National and state family and carer programs and peaks

The NSW Special Commission of Inquiry into the Drug 'Ice' and NSW Government response recommended that the new NSW AOD Family and Carer program be informed by the NSW Family and Carer Mental Health Program. This section provides an overview of that program and other family and carer related programs in Australia and NSW.

5.2.1 NSW Health Family and Carer Mental Health Program

Provisions in legislation (<u>NSW Mental Health Act 2007</u>) recognise the importance of and rights of carers to be involved in developing care and treatment plans for their loved one with mental health issues, and in the planning, delivery and evaluation of services, as well as having their own health and wellbeing needs addressed. This recognition provides impetus for family-focused mental health practice, involvement of carers and programs targeting the needs of family and carers.

Program Description

The <u>NSW Family and Carer Mental Health Program (FCMHP)</u> is a statewide program funded by the NSW Ministry of Health since 2005, and delivered in partnership between LHDs, JH&FMHN and five specialist community managed organisations (CMO): STRIDE, CatholicCare Wilcannia-Forbes, Mission Australia, One Door Mental Health, Uniting. The Mental Health Branch, Ministry of Health provides central coordination functions for the program including commissioning, monitoring, and facilitation of statewide meetings and training. The stakeholders work in partnership to improve the wellbeing of families and carers of people with mental health conditions, and the people they support.

The <u>NSW Family and Carer Mental Health Program Framework</u> outlines the key aspects of the program which has two main strategies:

- 1. To increase the capacity of mental health services to work with families and carers of mental health consumers by:
 - o increasing the knowledge and skills of staff to work with families and carers
 - \circ increasing organisational support to work with families and carers
 - o developing/ensuring appropriate resources to work with families and carers.
- 2. To improve the wellbeing of families and carers of mental health consumers by:
 - improving the initial linking/engagement of families and carers with the service
 - $\circ \quad$ increasing the knowledge and skills of families and carers
 - increasing support for families and carers.

The program offers a range of information, support and services which include:

- education and training packages that teach families and carers about mental illness and its management, including how to help build coping skills and resilience
- providing information, resources, one-on-one support, advocacy and coordinating support groups
- supporting families and carers with additional needs and cultural diversity
- providing clinical services and delivering health promotion activities.

Education, training, individual support and advocacy services are provided by the LHDs and CMOs, and where appropriate, the JH&FMHN. Families and carers are actively included and encouraged to participate in the design and delivery of these services.

Program Evaluation

A recent evaluation (Gordon, Grootemaat, Loggie, Rahman, & O'Shea, 2022) found the FCMHP is widely regarded as an important and successful initiative, well established in the mental health sector and has improved lives of carers over many years, decreasing levels of stress and burden. It was reported that CMOs, LHDs and JH&FMHN have contributed significantly to increasing the capacity of mental health services to work with families and carers.

A key finding was a strong sense among stakeholders that the program has embedded the inclusion of family and carers through building participation processes into practice. This has occurred through family meetings, needs assessment processes that include carer needs, and the inclusion of families and carers in support plans.

Other examples include carers working directly with clinicians to co-design programs, education and promotion resources. However, stakeholders also reported that there is some way to go before carer inclusion is fully embedded in services. It was recommended that the program consider minimum requirements to ensure all carers have access to

the key elements of the program (i.e. personal support, peer support, peer connections, education) and more flexible options for program delivery such as after-hours support and education activities, additional outreach support.

The scope of practice of CMO staff emerged as an issue for carers and program staff across a small number of LHDs. Some carers suggested that upskilling CMO staff to deliver counselling services would meet an important unmet need. Other stakeholders though felt that it was the LHDs' role rather than CMOs to deliver these services.

It was recommended that the program implement appropriate minimum training requirements for CMOs staff, including Trauma Informed Practice and group facilitation to ensure carers feel safe and included. The increasingly important role of peer workers within the program was also broadly recognised as an important and positive outcome for the program.

A further finding was that there are very few identified positions for Aboriginal and Torres Strait Islander staff across the program. A number of important suggestions were identified including recruiting Aboriginal and Torres Strait Islander peers to the program, providing extra resources to build partnerships with Aboriginal and Torres Strait Islander groups and building cultural capacity of program staff and other stakeholders.

Another output from the evaluation has been the development of a program logic for the FCMHP. The program logic provides a clear summary of the objectives of the program and the interaction between its different elements. It is expected that the program logic will be used as a practical monitoring and evaluation tool.

5.2.2 Carers Australia

<u>Carers Australia</u> is the national peak body representing Australia's unpaid carers, advocating on their behalf to influence policies and services at a national level. Their primary objectives are to:

- advocate for policy and service actions that support the caring role and enhance the health, wellbeing, resilience and financial security of Carers
- advocate for the inclusion of Carers as a priority group within mainstream and specialist service programs
- advocate to have caring recognised as a shared responsibility of family, community, business and government with the aim of achieving improved outcomes for carers
- undertake other policy, advocacy and service actions which the Board considers to be of benefit to Carers.

There is also the <u>Young Carers Network</u> for young carers aged up to 25 years old who provide unpaid care and support to family members or friends who have a disability, mental illness, chronic condition, an AOD issue or who are frail aged. This network provides information on general support services, a carer bursary program to assist with education needs, shared stories and information on events and opportunities.

5.2.3 Carers NSW

<u>Carers NSW</u> provides information, education and training, resources and referrals to support carers in NSW. It has developed a series of resources for carers of people using AOD which can be accessed on their site. They also provide information sheets (e.g. looking after yourself as a carer, what are emotional boundaries), videos outlining support services and links to useful services.

The <u>Carers NSW Young Carer Program</u> supports young carers through:

- linking them with practical supports that meet their needs, such as other services and programs
- providing information to young carers, parents and other stakeholders through a monthly eNewsletter
- developing resources to raise awareness of young carers in the community
- delivering <u>Young Carer Awareness Training</u> and other information sessions to help raise awareness of young carers in schools, universities and organisations.

5.3 Evidence based and evidence informed models and programs

This section outlines the evidence for models, services and programs and gives examples of each. Most programs incorporate a range of approaches, so the sections below are grouped firstly by outcome area and later by intervention type.

General comment

Recent systematic reviews have found there to be a scarcity of evidence-based treatments for families affected by another's AOD use (Rushton, Kelly, Raftery, Beck, & Larance, 2023). van Beek et al. (2023) for example, reported that there are a relatively small number of interventions or services aimed at family members. Some of the examples noted included Community Reinforcement and Family Training (CRAFT), Invitation to Change approach, SMART Recovery's Family and Friends program, the 5-Step Method, and independent self-help groups such as Al-Anon/Nar-Anon (van Beek, Velleman, de Bruijn, Velleman, & Goudriaan, 2023). Some of these interventions or services were primarily aimed at involving the family to encourage and mobilise the person using AOD to enter or remain in treatment, with only a few of the available interventions specifically designed for affected family and carers (McGovern et al., 2021). Some of these programs are outlined in more detail below.

5.3.1 Interventions that improve family functioning and relationships

Jointly delivered programs for people using AOD and their family members/carers

McGovern et al. (2021) conducted a systematic review of evidence for effective interventions to improve the wellbeing of family members affected by the AOD use of an adult relative. Behavioural interventions (behavioural strategies, CBT, skills training) delivered conjointly with the person using AOD and family members were found to be effective in improving the social wellbeing of family members, e.g. reducing intimate partner violence, enhancing relationship satisfaction and stability, and family functioning.

Programs that focus on parenting skills and the needs of children

McGovern et al. also reported on two types of interventions for parents and children affected by parental substance use—those that intervened with the parent to enhance parent skill and those that intervened with the child to address the impact that their parent's substance use has had upon them. They identified five trials which intervened with the parent using AOD to enhance their parenting skill and family functioning. In these trials, the affected non-using partner and/or child were typically involved to support change within the parent's behaviour (e.g. provide a means to practice the newly acquired skill, or to reinforce positive behaviour). Despite this indirect focus, McGovern et al. found the interventions were mostly effective at improving family functioning and relationships (McGovern et al., 2021). Unfortunately, no interventions fully addressed the complex multidimensional adversities experienced by many families affected by AOD use.

5.3.2 Interventions that improve mental health, quality of life, family functioning and coping

Group education and support interventions

Sanatkar et al. (2022) conducted a systematic review and, from 2257 records, identified only two evaluation studies examining interventions specifically designed for caregivers of people who use methamphetamine (Sanatkar et al., 2022). They also reviewed four qualitative accounts describing the experiences of caring for people who use methamphetamine. The results of the review suggested that effective treatment components include tending to caregiver concerns and providing training to enhance informational support and problem-solving skills. The two interventions identified in the review were the Matrix Model Intervention and an adaptation of the Family Wellbeing Program (Aboriginal healing intervention). These programs delivered group sessions to caregivers and provided information about the impact addiction can have on relationships and family dynamics, and support on how to address, and cope with, interpersonal conflicts. Both programs showed a reduction in symptoms of poor mental health and an increase in life satisfaction and quality of life experiences, although noting the research on the Family Wellbeing Program did not assess family member members directly but used feedback from service workers.

$\label{eq:psychosocial} \textit{Psychosocial interventions}-\textit{individual and group}$

Rushton et al. (2023) conducted a systematic review examining the effectiveness of psychosocial interventions for improving the wellbeing of family members (Rushton et al., 2023). Nineteen studies were included in the review. Some of the programs included in the review were CRAFT, 5-Step method, CBT, Stepping Stones, Treatment Entry Training (TEnT), Multifamily program, Al-Anon/Nar-Anon, Positive Psychotherapy and Brief Intervention. Several of these programs are offered in Australia and within NSW and are described in more detail further in this section.

Rushton et al. (2023) recognised limitations about their conclusions due to small sample sizes and methodologically weak-quality studies but overall both individual and group interventions demonstrated favourable outcomes with reductions in depression and stress and improved family functioning and coping. In addition,

Rushton et al. (2023) noted that the findings must be considered within the context of the varying theoretical underpinnings of the treatment for families. For example, CRAFT interventions were originally developed to encourage the person using AOD into treatment versus the 5-step method which is based on the stress–strain-information-coping-support model and understanding that families require support in their own right.

Despite the theoretical differences, common elements were seen across the treatments:

- an emphasis on providing families with education, support and coping skills
- promoting behavioural changes
- effective communication
- highlighting the importance of self-care
- mutual support and collective problem-solving (among group delivered interventions).

5.3.3 5-Step Method

A brief description is provided of the 5-Step Method because it is used as a program in its own right but also incorporated into other treatment/support packages. The 'stress-strain-information-coping-support' model emerged as a promising approach to reduce addiction family-related harm (Copello, Templeton, Orford, & Velleman, 2010a). It was developed on the basis of research on how families can be affected by a relative's AOD use and recognition that living with a highly stressful experience may lead to psychological and physical symptoms of ill health for the family members, other than the person using AOD (Copello, Templeton, Orford, & Velleman, 2010b). The model has principles that focus on empowerment and agency for families (Orford, Copello, Velleman, & Templeton, 2010). Table 3 outlines the five steps (Copello et al., 2010b, p.87).

Step	Description
1. Listen, reassure and explore concerns	 Allow family member to describe situation Identify relevant stresses Identify need for further information Communicate realistic optimism Identify need for future contacts
2. Provide relevant, specific and targeted information	 Increase knowledge and understanding Reduce stress arising from lack of knowledge or misconceptions
3. Explore coping responses	 Identify current coping responses Explore advantages and disadvantages of current coping responses Explore alternative coping responses Explore advantages and disadvantages of alternative ways of coping
4. Discuss social support	 Draw a social network diagram Aim to improve communication within the family Aim for a unified and coherent approach Explore potential new sources of support
5. Discuss and explore further needs	 Is there a need for further help? Discuss possible options with family member Facilitate contact between family member and other sources of specialist help

Table 3. Five steps to support family members affected by addiction problems.

Even though the components are described as part of five steps, they can be combined and even delivered over one single meeting if this is necessary. There are two caveats - family members have reported the first step is one of the most important ones, they value the opportunity to tell their stories and be listened to by someone who has time and is non-judgemental. Also, premature discussion of coping methods (Step 3) may leave family members feeling that they are not coping in the 'right way' and they may perceive the discussion of coping behaviours as a criticism of how they are managing in the situation.

A criticism of the model is its narrow focus on family members only and for not broadening the focus to include coping with strain in family relationships (Selbekk, Sagvaag, & Fauske, 2015). Selbekk et al. (2015) explain that it is important

to have flexibility and to also consider social-ecological models, i.e. services for individuals and families and service provisions that address relationships, systems and communities.

Van Beek et al (2023) evaluated the 5-step method delivered in the Netherlands for family members affected by a relatives' AOD use or gambling (van Beek et al., 2023). It involved studying routine clinical care (mostly for AOD use) and delivered via videoconferencing or face-to-face and by trained clinicians. Overall, they found lower family burden and improved coping. Delivery of the program via videoconferencing was found to have similar results to face-to-face.

5.3.4 Mutual aid

The SMART Recovery research report summarises evidence on positive outcomes from mutual aid (Argent, 2021). Mutual aid, known as peer support, enables peer-to-peer learning. Peer support is defined as the process of giving and receiving non-professional non-clinical assistance between people with similar experiences or circumstances. Sharing experiences, knowledge and encouragement and providing social, emotional and practical support. Peer-support groups can be made to be widely available and cost effective and found to amplify and extend treatment effects and enhance long term recovery.

SMART Family & Friends Groups

<u>SMART Family & Friends</u> is an evidence based, secular, non-judgmental program committed to harm minimisation for addiction. It assists anyone affected by the behaviours of concern of someone close to them. It is a self-management program. SMART Family & Friends was adapted from SMART Recovery, a strengths-based mutual aid (peer support) program for people struggling with various problem behaviours of all kinds. SMART Recovery uses evidence-based principles and strategies including Motivational Interviewing and Cognitive Behaviour Therapy⁶ and the program draws influence from the 5-Step model.

The program offers online and face-to-face support groups. The groups are run by trained facilitators who may have had their own experiences as a family member affected by another's relationship with AOD, gambling or other behaviours of concern. It is noted that trained facilitators can support program fidelity.

The SMART Family & Friends program supports family and friends to develop more effective coping strategies and to find a greater sense of fulfilment in their lives by focusing on themselves as opposed to the person with AOD use. The program aims to teach self-empowerment and self-reliance, using tools and techniques for self-directed change. It provides a practical toolkit with the aim to improve the quality of life, coping skills and support system of the supporter of the person with AOD use.

A self-help manual covers a range of topics including:

- Managing emotional upsets
- Changing unhelpful responses
- Challenging unhelpful thinking
- Improving communication
- Setting healthy boundaries
- Developing better functioning support systems and lifestyle balance
- Coping and regaining control.

There is an ongoing evaluation of the SMART Family & Friends program enabled by two research grants. Unpublished results presented at a recent Turning Point webinar (Rushton, 2023) showed increased participant attendance and satisfaction. Outcomes included decreased psychological distress, stress symptoms, impact on family member and total family burden and improved coping. It was concluded that there is strong evidence for the feasibility of the program delivered via conferencing with important benefits of providing treatment to families.

Al-Anon Family Groups

<u>Al-Anon</u> Family Groups is a 'fellowship' for family and friends affected by a person's AOD use. Alateen is the recovery program for young people and the groups are sponsored by Al-Anon members. Alateen provides support for adolescents affected by the problem drinking of a parent or other family member. The program of recovery is adapted from Alcoholics Anonymous and is based on the Twelve Steps, the Twelve Traditions, and the Twelve Concepts of Service. It is primarily based on mutual support.

<u>Nar-Anon</u> is a similar 'fellowship' with a specific focus on drug use. Nar-Anon Family Groups are self-help support groups for families and friends of a person with AOD use.

⁶ See research report <u>https://smartrecoveryaustralia.com.au/wp-content/uploads/2022/01/SMART-Recovery-Australia-Research-FAQ.pdf</u>

Parent coaches - peer support

Carpenter et al. (2020) evaluated the feasibility and acceptability of a phone-based parent-to-parent support program, in which parents who have had children with AOD problems provided support and guidance to other parents seeking help about their child's AOD use (Carpenter, Foote, Hedrick, Collins, & Clarkin, 2020). Parents completed a 2.5-day coach workshop and 6-months of ongoing training and support in the Invitation to Change Approach (ITC), a program blending evidence-based strategies for addressing AOD use (i.e. CRAFT; Motivational Interviewing and Acceptance and Commitment Therapy). Trained parent coaches provided support and guidance to the participant parents for up to 8 weeks. The coach training program was rated as very satisfying, useful, and coaches would recommend the training to other parents. Being trained to provide peer support in the context of evidence-based practices was rated as highly acceptable and useful. Parents receiving peer-to-peer support reported improvements in their emotional distress and the use of helping strategies. Parent-to-parent phone-based coaching can introduce families to evidence-based practices and support, not unlike other evidence based peer support programs. The authors concluded that remote parent-to-parent coaching appears promising for providing emotional and evidence-based informational support to family members parenting a child with AOD use.

5.3.5 Education and support groups

Support groups facilitated by experts

Hoeck and Van Hal conducted a small-scale qualitative study based on in-depth interviews with parents of young people using AOD (Hoeck & Van Hal, 2012). They focused on the parents' experiences of having a child who uses AOD and attending a support group. All parents displayed feelings of stress and strain. It was reported parents were highly satisfied with participation in a support group, appreciating the expert status and knowledge of the facilitator (social worker) and the provision of accurate information. Participants raised concerns about the attitude and knowledge of their GP who they felt underestimated the problem and did not seem well informed about AOD use and referral services. Given the research was conducted some time ago, such findings could be different now with a more contemporary focus and understanding of AOD use and its impacts. Hoeck and Van Hal (2012) suggest that the interaction within a support group represents a framework in which shared experiences, an increased understanding of their needs and a focus on themselves favour participants' health outcomes. The knowledge about addiction (treatment, prognosis) of the social worker leading the support group can be used to motivate the group and helps the group to work in a constructive way, aiming to manage stress by recognising feelings and gaining insight into the situation.

SteppingStones and Stepping Forward

The SteppingStones program is delivered by FDS and promoted through the FDS website. The program runs over two consecutive weekends and combines information sessions, participant sharing, experiential learning and group work. It aims to support the development of effective coping, and a more hopeful and enjoyable life regardless of the actions of the person using AOD. It also supports safety planning and information on where to get help. Providing information and emotional and practical support has been shown to improve family well-being and coping (Gethin, Trimingham, Chang, Farrell, & Ross, 2016). In their evaluation of the program, Gethin et al. (2016) reported that most of the participants are parents of adult children (90%), with partners, siblings, adult children, grandparents and friends comprising the balance. They also reported a recent increase in participation by partners of newly retired men, where retirement is accompanied by substantially increased alcohol or marijuana use.

Stepping Forward offers two-hour community education forums covering topics from seven common areas of challenge for families such as Family Stages of Change, Effective Communication, Dealing with Conflict etc.

5.3.6 Case management

SAMHSA (2020) reports that case management services can help families address problems within larger systems of care, e.g. healthcare, education, legal and childcare-related issues. SAMHSA report that these issues commonly occur for individuals and families and should be a standard part of family-based AOD treatment. Family peer recovery support services offer families the valuable opportunity to learn from others who have had similar experiences (SAMHSA, 2020).

5.3.7 Online information, services and resources

Distance-based services, such as telephone and online services, are well placed to overcome many of the help-seeking barriers faced by partners, as well as protecting identities and privacy in smaller communities (McCann & Lubman, 2018).

Online education and support programs

In their consultation paper, Skinner et al. (2021) presented a review of literature and reported that online delivery of education and support programs have additional benefits to face-to-face programs: they are accessible anytime and anywhere which may increase participation and engagement, content quality is consistent, cost of delivery is lower compared to face-to-face support and online delivery is scalable for larger groups. For people with low literacy levels, other resources such as audio or visual (e.g., podcasts, videos, DVDs) may be beneficial.

Online counselling

Online information and support (e.g., counselling) can also be an effective approach to managing stigma that may be felt by family and friends when accessing AOD information and services (Skinner, Duraisingam, et al., 2021). In their qualitative study of online counselling, Wilson et al. (2017) found that partners wanted to talk about their concerns with a non-judgemental professional. However, the majority wanted advice, assistance with problem-solving situations around change, coping, and the help-seeking process, along with specific information or referral details.

Skinner et al. (2021) also reported that, while online information and resources are an important and useful option for concerned family and friends, ADF commissioned research indicated a strong preference for face-to-face counselling by family and friends, especially for people from Aboriginal and Torres Strait Islander communities (Skinner, Duraisingam, et al., 2021). In addition, there is a clear need for culturally appropriate resources tailored to meet specific cultural groups' needs. These information and support resources need to address cultural taboos related to AOD within particular communities.

Some examples of online programs, services and resources are included below. Along with information, many provide referral services and supports for individuals.

Family Drug Support Australia

The Family Drug Support Australia (FDS) provides contemporary information on AOD use for families of people who use AOD. FDS operates a National 24-hour, 7 day a week telephone support service for families and live video chats by support workers are available for members. FDS provides family support groups in NSW and other jurisdictions and online. The FDS website promotes a range of educational and interactive programs for families, friends and workers through their Stepping Forward, Stepping Stones, and Support the Family programs. There is also an online counselling resource designed to provide support for family and friends of individuals experiencing problems with crystal methamphetamine and/or other drug use. The program consists of a series of online videos following the progress of a Family Drug Support group focused on helping family and friends become more resilient and better able to cope with their relative's drug use. The resource is helpful for those in regional and rural communities who do not have ready access to face-to-face support group meetings.

FDS Online provides a series of short online videos which follow a support group's journey. It has been available since 2017 and accessed 28,000 times. An evaluation was conducted (published June 2023), consisting of interviews with viewers six months after completing the videos (n=6) and a survey (n=355). It was reported that all interviewees felt very positive about the videos; they found the videos were relatable and they learned valuable information for their own situations. The videos were reported to reduce feelings of isolation and stigma and better able to cope after the experience. Some suggestions were made to further enhance outcomes.

Cracks in the Ice

<u>Cracks in the Ice</u> is an online toolkit providing evidence-based and contemporary information and resources about crystal methamphetamine for the Australian community, including concerned community members, users, their friends and family members, health professionals and emergency service workers, and schools. It was developed in response to the Final Report of the National Ice Taskforce (Commonwealth of Australia & Cabinet, 2015). The report stated that "The first priority must be supporting families, workers and communities to better respond to people affected by ice." (Commonwealth of Australia & Cabinet, 2015). Champion et al. (2018) describe the co-development process of the Toolkit (Champion et al., 2018). The fact sheets and information on the Cracks in the Ice website were developed and/or reviewed by researchers at the Matilda Centre for Research in Mental Health and Substance Use, University of Sydney, and the National Drug Research Institute, Curtin University⁷.

There are several types of information and supports provided on the web page, with very practical and helpful information and strategies:

• Coping with stress and uncertainty during COVID-19

⁷ The following link contains all the sources used to inform the content <u>https://cracksintheice.org.au/faq/references</u>.

- Concerned about someone using Ice
- Starting the conversations
- When someone you care about won't seek support
- How to protect yourself and others
- What type of help is available.

Your Room

<u>Your Room</u> is a joint initiative by NSW Health and St Vincent's Alcohol and Drug Information Service (ADIS). Your Room is a website that provides information and resources about AOD. The website has a specific section that provides information to support families in NSW to reduce the harms caused by AOD, find support services and understand treatment options. It includes information on other programs such as those described here (e.g. FDS, FFSP).

Family and Friends Support Program

The <u>Family and Friends Support Program</u> (FFSP) was funded by the Australian Government in 2016 as an enhancement to the <u>Cracks in the Ice</u> online toolkit. The program was developed in collaboration with researchers from the Universities of Sydney, Newcastle, New South Wales and Bath and members of the Addiction and the Family International Network. A detailed summary of the program and access to the program is available via <u>Cracks in the Ice</u>. This program is currently undergoing a formal evaluation⁸.

FFSP is an online resilience and wellbeing program to support affected friends and family members of people who use methamphetamine. The FFSP is comprised of two key components:

- 1. an online support program evidence informed program providing affected family and friends with a tailored, evidence-informed website that addresses their needs in supporting a person using crystal methamphetamine 'ice'
- 2. a training program for health workers an evidence-based training and accreditation program for health workers (the 5-Step Method) to improve their capacity to support family members and friends of people using Ice.

Although a key focus is on Ice, the FFSP also covers AOD, domestic and family violence (DFV) and those living in rural and remote locations. These programs mostly have the same components:

- Online program to help family and friends manage their situation
- Helpful activities
- Real stories what it's like supporting someone using ice (AOD, DFV)
- Training resources for health professional

A separate web page is provided on information and resources about Ice for Aboriginal and Torres Strait Islander peoples. There is also a moderated forum, *Breathing Space*, which is a purpose built, moderated, and secure social network, where people can seek support from clinicians and each other to help them improve their wellbeing and resilience. The website indicates that Breathing Space has been tested in clinical trials and is now being offered to family and friends of people supporting someone using AOD. Breathing Space communities function as 'closed groups'; in order to join a specific community, a person will need to share common issues, experiences, or concerns with the people in that group. This sort of community offers greater privacy and confidentiality than an 'open' social network.

Young people caring for friends

<u>ReachOut</u> provides practical ways and resources for young people to help a friend with drug addiction see <u>https://au.reachout.com/articles/how-to-help-a-friend-with-drug-addiction.</u> Online forums also provide a way to reach out and gain some support.

Path2Help

The Alcohol and Drug Foundation (ADF) Information and Support Program for Family and Friends includes a digital portal that provides high quality, accurate and personalised information and support to meet the needs of family and friends (<u>Path2Help</u>). The Path2Help portal aims to provide the most up-to-date and 'credible' resources to assist people looking for ways to support their loved ones who use AOD.

⁸ Developers: Kay-Lambkin F,K; Chapman, C; Teesson, M; Ross, K; Geddes, J; Hunt, S; Velleman, R; Velleman, G.

Information and support service referrals are determined through the ASSIST (Alcohol, Smoking and Substance Involvement Screening Test) model which can help to identify the risks associated with AOD use and explore a person's motivation to change. The content and information provided by Path2Help is intended as a guide to steer people towards the most appropriate information and services for their specific circumstances as identified by the portal.

Apps

Chapman et al. (2018) systematically reviewed existing applications (apps) in the iTunes and Google Play Stores to determine the existence, composition, and quality of educational smartphone apps about methamphetamines, including ice (Chapman et al., 2018). Overall ratings on identified apps were highest for functionality (ease of use and navigation), rated as acceptable to good on the majority of apps but noting the overall quality was low, and overall ratings were lowest for engagement, i.e. interactivity, interest, and suitability for target audience. Their study demonstrated a shortage of high-quality educational and engaging smartphone apps specifically related to methamphetamine.

Phone based

Ryan-Pettes et al. (2019) investigated the feasibility and acceptability of mobile phone–based aftercare support in a population of caregivers with adolescent children in treatment for AOD use (Ryan-Pettes, Lange, & Magnuson, 2019). Caregivers reported that text messages with the following content would be helpful: ways for improving communication with their child, reminders and encouragement to use consequences, suggestions for getting their child involved in positive activities, and messages with tips for monitoring their child's AOD use. Caregivers also reported the desire for additional counselling for the child and general family/caregiver support (26%). The study suggested that mobile phones are feasible and desired to deliver treatments that provide support to caregivers in their parenting role.

Web based

Ploeg et al. (2017) conducted a rapid evidence review of web-based interventions. They found that these interventions may result in improved mental health, general caregiving, and general health outcomes, but the effects and improvements on study outcomes varied (Ploeg et al., 2017). It was not clear which types of web-based interventions were most effective and for whom.

There were a range of interventions, e.g. information/education (I/E) only, plus peer support, I/E plus professional support, all I/E plus monitoring and professional support, monitoring plus peer and professional support. Although more work needs to be done in this area, potential benefits of web-based interventions are that they may be less costly than those involving face-to-face support from professionals, and they may be more accessible to caregivers.

5.4 A family focused and systems approach

5.4.1 Family focused approaches

Family support programs and parenting interventions are most effective when they target multiple domains of family life, are strengths-based, intensive, prolonged, and focus on improving outcomes for family and friends - adopting a 'whole family' approach is essential (Whittaker et al., 2014).

The US based Substance Abuse and Mental Health Services Administration (SAMHSA) updated <u>Treatment</u> <u>Improvement Protocol (TIP)</u> provides information and guidance on evidence-informed, family-based interventions and family counselling approaches for AOD use (SAMHSA, 2020). It describes the underlying concepts, goals, techniques, and research support for each approach. SAMHSA (2020) describes specific family-based treatments that can be used effectively to help families improve their functioning and enhance recovery. These include Psychoeducation, Multidimensional Family Therapy (MDFT), Behavioural Couples and Family Therapy, Brief Strategic Family Therapy (BSFT), Functional Family Therapy, Solution-Focused Brief Therapy, Network Therapy, Multisystemic Therapy (MST), Systemic Motivational Therapy And CRAFT. See Appendix II for a brief description of each of these interventions.

Regardless of approach, all family-based treatments share certain core aspects including: improving the health and well-being of the whole family, not just the person using AOD; respecting the value of family and other social relationships as a key part of recovery; and meeting harm-reduction goals other than abstinence, which can still benefit the family and the individual.

Kourgiantakis et al. (2021) conducted a scoping review⁹ to examine family-focused practices in both AOD use and gambling adult treatment (Kourgiantakis et al., 2021). Based on 95 studies in the review (mostly alcohol or drugs, 91%), family involvement improved relationship satisfaction, enhanced coping skills, and improved family functioning. It also decreased distress for the person with AOD use and reduced their chance of relapse. Studies recommended that families need more than one treatment option to meet their specific needs. Studies also recommended more culturally adapted interventions and increased training for social workers and other service providers in primary care on how to provide family-focused care. Families should have greater access to information on how to navigate services in addictions and mental health. Kourgiantakis et al. also highlighted the importance of overarching models and theoretical frameworks guiding interventions. These frameworks influence service providers and the type of services they deliver to families. Key findings also indicate that access to psychoeducational, non-judgmental, therapeutic services results in family members' increased knowledge of addictions and encourages them to seek further support.

In the studies of family interventions that focused on the family's needs and did not include the person with AOD use, the interventions included professionally led support services, peer support or self-help groups, web-based counselling services, 5-Step Intervention and coping skills. None of the studies included in this category identified using a harm reduction model or a recovery-oriented approach, although these approaches are used broadly in addiction treatment and are part of some programs described in this report.

NSW family focused recovery framework

NSW Health is implementing a <u>Family Focused Recovery Framework</u> which guides services in improving support to families where a parent lives with mental health issues and has dependent children through implementing a family focused approach.

5.4.2 Family inclusive practices

Recent societal changes and advances in knowledge have impacted the AOD sector, such as new patterns of AOD use, greater awareness of family inclusive practice issues, foetal alcohol spectrum disorder and child protection issues (Commonwealth of Australia & Cabinet, 2015) (Skinner, Kostadinov, et al., 2021). The <u>NSW Non-Government Alcohol</u> and other Drugs Workforce Development Plan 2016–2022 is underpinned by the principle of harm minimisation, i.e. it seeks to enhance workforce capacity to prevent and reduce the impact of AOD-related harm on individuals, families and communities. Enhancing both specialist and non-specialist capacity to prevent and reduce AOD-related harm is a primary intention of the Plan. A key activity includes family sensitive/inclusive practice.

Family inclusive practice recognises the impact of an individual's AOD use on their entire family, and as such addresses the needs of all family members. This includes identifying and addressing the needs of adult clients as parents, as well as the needs of their children, in order to ensure that as parents they are supported and child wellbeing and safety are maintained (Skinner, Kostadinov, et al., 2021).

SAMHSA (2020) report that the key to developing and implementing family-based AOD treatment and services is to ensure treatment programs adopt a family-centred culture. This means administrators, directors, supervisors, and other leadership should work together to ensure existing treatment and services are family friendly, tailored to families' full range of needs, and based on empirical evidence. A family-centred culture means an organisation includes family members and their needs throughout the treatment and service provision process, including as part of engagement and in shaping the physical program environment. Integrating family counselling and program elements requires education and buy-in among staff as well as the families.

The following key principles have been identified by SAMHSA (2020) in AOD services which work with families:

- Recognising the therapeutic value of working with family members
- Incorporating a non-blaming, collaborative approach
- Having harm reduction goals other than abstinence
- Expanding outcome measures of "successful" treatment to include the health and well-being of the entire family, as well as the individual with the AOD use
- Acknowledging the value of relationships within the family and extrafamilial social networks as critical sources of support and positive reinforcement

⁹ A scoping review, as defined in the paper, is "a form of knowledge synthesis that addresses an exploratory question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting, and synthesizing existing knowledge".

- Appreciating the importance of adapting family counselling methods to fit family values and the cultural beliefs and practices of the family's larger community
- Understanding the complexity of AODs and the importance of working with families to manage family functioning, physical and behavioural health, and well-being.

5.5 Programs that support parents with AOD use, their partners and children

Effective interventions, delivered in the early years, have the greatest positive impact on children's development and their life course trajectory. Taking care of the needs of children and young people whose parents and/or other family members or friends use AOD can occur in a variety of ways, such as supporting parenting practices or direct treatment for the children.

5.5.1 Programs for all members of the family

<u>CatholicCare</u> provides a Family Recovery program for family members and individuals dealing with AOD use or gambling behaviours and related mental health issues. The service is available to family members, regardless of whether or not the person using AOD seeks help. Family Recovery consists of four programs:

- *Relationships in FOCUS* for partners and other adult family members of people using AOD (or gambling), past or present.
- *PAUSE Parents* for parents of adolescents and young adults using AOD. The program covers communication, boundaries, adolescent development, drug education, mental health concerns and parenting expectations.
- *Pathways to Change* for young people 12-18 years. It provides a safe environment for young people to consider their AOD use and to develop strategies to control or stop their use.
- *Kaleidoscope* age-specific groups designed for children 5-18 years who have been affected by someone else's AOD or gambling behaviour.

<u>Odyssey House Parents and Children's Program</u> enables parents (including single mothers and fathers, as well as couples) to undertake treatment whilst their children (0-12 years) live with them. Clients reside in a purpose-built Family Recovery Centre which provides a home where parents can maintain care of their children during their recovery while we help them develop the skills to establish and manage a safe and healthy family home.

Lives Lived Well is a registered charity that provides support for people in Queensland, NSW and South Australia who are impacted by AOD use or problems with mental health. They provide a range of services for families, including parents, siblings, partners and friends. The services include information sessions, individual support, family therapy and support groups. The Kids in Focus program works with parents affected by AOD so that they feel supported and are better able to cope with family life. This program is delivered in partnership with other service providers, such as the Benevolent Society Early Years Centre and Wesley Mission Queensland. There is also a live-in Family Recovery program based in Logan and another for parents with younger children in Parkhurst.

5.5.2 Programs addressing the needs of mothers and children

Some treatment programs for mothers who use AOD, focus on specific aspects conducive to motherhood. For example, Chou et al. (2020) found positive impact of mothers' experiences in family-centred AOD treatment, aligning with previous literature that suggests mothers are more engaged in treatment when their children remain in their care (Chou, Cooper-Sadlo, Diamond, Muruthi, & Beeler-Stinn, 2020). Children benefited from the program and had access to the therapeutic day care in addition to individual therapy and case management services. Mothers identified that both the individual and family treatment programming directly benefited their children. Chou et al. (2020) suggested that treatment providers should consider the importance of directly addressing children's needs because, while children can act as a motivator to mothers in recovery, they can also act as stressors that may contribute to relapse if not also considered during their mothers' treatment.

5.5.3 Examples of programs that support outcomes for children of parents using AOD

Odyssey House Victoria - Programs

The <u>KODY project</u> is a partnership between Kids First and Odyssey House. It offers a program to support fathers to improve their parenting, reduce family violence and address substance use concerns; to enhance their family's safety and wellbeing. Specialist support is provided while fathers participate in the KODY Caring Dads program and also engage in AOD counselling, while parents and their children have the opportunity to work with Kids in Focus. Research

on the program is currently being conducted (Kertesz et al., 2022) and is due to be completed in 2024. It may provide useful information for later consideration.

<u>Kids in Focus</u> (KIF) is a specialist child and family support program that provides a range of intensive services for families affected by parental AOD use. The program aims to identify and address both the needs of the parents and their children. KIF provides outreach case management providing evidenced based interventions for vulnerable families. Services include:

- Information and support
- Home based parenting education and support
- Counselling and case management
- Recreational and therapeutic groups for children and their families
- Child and family activities to enhance social connections
- Facilitated access to rehabilitation
- Financial Counselling
- Antenatal care through our partnership with the Royal Women's Hospital
- WADS program (Women's Alcohol and Drug Statewide Service providing specialist clinical services to pregnant women with complex AOD use)
- Post-natal follow up and support.

The KIF program offers secondary consultation though telephone advice and support, providing assistance with information, skills development and problem solving. Opportunities also exist for professional development and training.

CICADA Centre NSW

The CICADA Centre NSW brings together three teams of experts from the Foetal Alcohol Spectrum Disorders (FASD) Clinic, Family Service and the Adolescent Drug and Alcohol Service, at The Sydney Children's Hospital Network to assist children, adolescents, families and NSW health professionals to build leadership and research into the prevention of harm to children and adolescents from drugs and alcohol. Among the range of services and supports is the CICADA Family Service, a health service for children and adolescents, aged 0 to 18 years, whose parents have drug and alcohol related issue. Families will be seen by a Paediatrician and Psychologist to assess the needs of the children and intervention and/or recommendations will be provided. In its earlier iteration, Teenlink, research found the service builds resilience and positive parenting capabilities and skills (Zehetner, latrou, Lampropoulos, & Phillips, 2017). The Adolescent program also supports young people presenting to hospital with drug and alcohol problems.

Useful resources on the CICADA website include:

- Families & Friends Affected by the Drug & Alcohol Use of Someone Close
- Talking to Children about Addiction

Holyoake

<u>Holyoake</u> is a non-profit organisation that offers programs to support those who are affected by AOD use, or related mental health issues. There are a range of counselling services (face-to-face, phone and video counselling) that use evidence-based approaches such as Motivational Interviewing, Cognitive Behaviour Therapy, Acceptance Commitment Therapy, Mindfulness, Expressive Therapies, Narrative therapy, Trauma Informed Care, Culturally sensitive practice, Family systems theory, Integrated care and harm minimisation. Holyoake offers special programs for children and young people who may be affected directly or indirectly by AOD use or related issues. Their programs include:

- Attachment Art and Play Program family sessions for caregivers and their child/children who have been impacted by their own or significant other's AOD use. Supported by a therapist, families use art and play to build the caregiver-child relationship, reduce parental stress and improve communication.
- Young People's Program involves 1:1 sessions for young people aged 3-17 years who are impacted by parental or significant other's AOD use. The young person is supported to develop the knowledge and skills to cope with their experiences and foster an increased sense of self-esteem.
- Adolescent Program involves 1:1 counselling with a counsellor to support young people aged 12-17 years to address their own AOD use, and to gain confidence, stay safe and reduce the harm of substances.

• Child Parent Relationship Training - group program for caregivers to develop a greater understanding of their children's emotional needs and to communicate more effectively.

5.6 Other jurisdictions example

5.6.1 Victorian AOD programs and approaches that support family and carers

As with NSW, other state-based AOD websites, both for those who use AOD and their families and carers, describe local services and also bring together information and services and supports available from other providers, e.g. links to FDS. However, there are some specific programs and approaches that are useful to report on in the context of this review.

In Victoria, for example, AOD treatment services adopt a family-focused approach. They engage families and support people in assessment, treatment planning and recovery. These agencies must consider the needs of family members and dependent children throughout the treatment process with the aim of reducing the harm to families caused by alcohol and other drug use.

A range of support services for families and support people, as well as peer-support services in Victoria can assist the individual and their families and support people through the treatment and recovery process.

Family drug support services are available through selected community health providers across Victoria. Providers deliver programs that are flexible and meet local population need and demand. Activities include peer support, groupbased support, support for young people whose parents are affected by drugs, targeted support for siblings, grandparents, culturally and linguistically diverse communities (CALD) and Aboriginal people, individual support (such as counselling) and information sessions.

Family Drug Help, delivered by the Self Help Addiction Resource Centre (SHARC), provides services that aim to strengthen the physical and mental health of families dealing with a loved one's AOD use, and support the family's ability to cope with their own situations. It provides a confidential 24-hour helpline, and access to information and referral to support groups and family counselling.

The Victoria Health Department also funds family drug education workshops through a consortium of Turning Point, SHARC and The Bouverie Centre. The <u>BreakThrough Ice Education for Families Handbook</u>¹⁰ is an educational resource for families impacted by a person's use of ice. It includes three sections:

- Facts types of drugs, reasons for use, ice and effects, withdrawal, mental health
- Strategies family relationships and roles, stages of change, caring for young people, self-care, boundaries, safety plans, etc
- Help support, assistance and professional help.

In addition to the one on Ice, there is <u>BreakThrough Families understanding addiction</u> which provides information and activities. There are also online BreakThrough sessions that help connect families and carers with others who share similar experiences.

5.7 Principles in designing programs

5.7.1 Getting in early

Early year's interventions, and 'earlier' interventions, are more likely to lead to better outcomes for children and families than interventions which are initiated when problems are severe or entrenched (Whittaker et al., 2014) 'Earlier' interventions with families and carers are more likely to prevent problems escalating and/or recurring.

The Final Report of the National Ice Taskforce (Commonwealth of Australia & Cabinet, 2015) noted that the ability of general practitioners to screen patients for potential problems and deliver appropriate interventions, or provide connections with Community Support Services, had great potential to reduce harms not only to the individual, but also the family and broader community.

¹⁰ This resource is by Turning Point, SHARC and The Bouverie Centre and developed by <u>Readymade productions</u> in collaboration with <u>Family Drug</u> <u>Support</u>. Funding was provided by the Australian Department of Health and Aged Care through the National Ice Action Strategy (2015).

5.7.2 Codesign

Co-design and action research has demonstrated the value of in-depth and collaborative engagement between service providers and family and carers in reshaping services to enhance the range and quality of support provided for family and carers (Palmer Du Preez et al., 2022). Gendera et al. report that "Taking account of culture and strength-based community-embedded approaches—as sources of identity, healing and reducing the impact of stigma and shame for family supporters and in AOD treatment—has vital practice and policy implications' (Gendera et al., 2022, p.1436).

5.8 Workforce development

5.8.1 Essential capabilities

Workforce development plays a key role in delivering quality treatment services to individuals and families affected by AOD use. Given the importance of family-centred approaches, workforce development efforts should orient all staff to the importance of engaging family members in the treatment process and providing family-centred services (SAMHSA, 2020).

All clinical staff need training in how AOD use affects family systems, family dynamics, and initiation and maintenance of family recovery. SAMHSA recommends recruiting counsellors who are interested in and comfortable with working with families and prioritizing candidates with specific education, training, lived experience, or professional history in working with families.

They suggest that peer recovery support specialists and recovery coaches, including those who have lived experience as a family member of someone using AOD, can also be valuable members of the clinical team.

Counsellors need specific knowledge, attitudes, and skills to shift from an individual to family systems focus in their approach. While core competencies for working with families differ among professions, all providers should be able to understand the complexity of the clients' family networks and interactions with their families (Gerhart, 2018, cited in (SAMHSA, 2020).

5.8.2 Examples of capacity building for NSW Health and NGO workforces

There are some existing training and resources available in NSW to support staff capabilities in working with family, carers and friends of people using AOD. There are also some resources available to support organisational change towards family include practices. Examples include but are not limited to:

- Training/education:
 - NADA's online training for NGOs and NSW Health services and tools and resources to strengthen family focused practice, including Engaging with Families and Significant Others in the AOD sector
 - FDS <u>Support the Family Improve the Outcome</u> workshops for drug and alcohol, mental health, youth and family services. These assist workers to understand successful models of change, 5 stages that families experience, communication, building resilience and psychoeducation.
- Organisational change:
 - NADA's Tools for Change: a new way of working with families and carers This resource contains a range of interventions, practice tips, service models, resources and training organisations to assist services in working with families. Tools are included such as template policies for working with families, a family inclusive practice workplace audit, assessment tools, checklists and a list of family and carer support services.
 - <u>ADF's Power of Words</u>: is a practical guide and desktop flip book designed to support healthcare and other professionals working with people who use alcohol and other drugs to reduce stigma and improve health outcomes.

Specifically, they should understand:

- How their own family histories and issues affect their interactions with and perceptions of the dynamics of families in AOD treatment
- Systems concepts, theories, and techniques foundational to family-based interventions
- Diverse cultural factors that influence the characteristics and dynamics of families and couples
- Risks and benefits of couples- and family-based interventions
- How, when, and why to involve clients' families and significant others in treatment and recovery
- Effects of AOD use on family communication, roles, and dynamics.
- Characteristics of families, couples, and significant others affected by AOD use.

5.8.2 NSW training and resources for service providers

NADA in partnership with FDS and the NSW Ministry of Health, developed training and resources for the AOD sector and other primary health contacts to build the capacity of workers to better support families who are impacted by someone else's AOD use. The <u>NADA Tools for change</u> notes that the goal of educating staff about working with families and carers is to increase staff (and therefore client) confidence and awareness of the role of family involvement in prevention, treatment, recovery and relapse. Increasing staff knowledge of the family as a unit and the influence of the ecological setting with which the AOD use occurs should be one outcome of staff education activities (Network of Alcohol and other Drugs Agencies (NADA) Publications, 2009).

5.8.2 Workforce development for working with families where a parent uses AOD

Emerging Minds

Emerging Minds is dedicated to advancing the mental health and emotional wellbeing of Australian infants, children, adolescents and their families. The organisation leads the National Workforce Centre for Child Mental Health, delivered in partnership with the Australian Institute of Family Studies (AIFS), the Australian National University (ANU), the Parenting Research Centre (PRC) and the Royal Australian College of General Practitioners (RACGP). It develops mental health policy, interventions, in-person and online training, programs and resources in response to the needs of professionals, children and their families.

The <u>Emerging Minds AOD learning site</u> provides a learning pathway for practitioners working with adults, whether as a generalist practitioner or as an AOD specialist. It focuses on understanding the potential impacts on a child of their parent's AOD use and working with parents to support children's long-term mental health and wellbeing.

There is a suite of parental AOD e-learning courses for practitioners working in all adult-focused services who engage with adult and family adversity. The foundation course, The *Impact of Parental Substance Use on the Child*, provides an introduction to the impact of parental substance use on children. The core course, *Parental Substance Use and Child-Aware Practice*, includes a guide for practitioners to engage with parents in conversations about their children's social and emotional wellbeing where substance use and other co-existing issues may be present.

The courses were developed in collaboration with a number of stakeholders from academia, AOD services, children and family services, child mental health experts and with parents with lived experience of problematic substance use and other co- existing issues. A comprehensive literature review was undertaken into the effects of parental substance use on Australian children and the intersection with other societal issues.

The PERCS Conversation Guide has been developed by Emerging Minds from Let's Talk, an evidence-based intervention with parents with mental health issues, as a way of thinking about their relationships with their children.

Toolkit for taking a whole of family approach to care

A useful resource is the Practitioner Toolkit: Getting it right for children and families affected by parental problem alcohol and drug use (Whittaker et al., 2014). Although some of the literature is dated, the key principles are sound and relevant. The toolkit consists of a *philosophy of approach, good practice guidance* and *practice 'tools'*, underpinned by evidence-based information and advice. It focusses on integrated care and a whole of family approach. This resource may be updated in the future.

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Appendix I: Outcome Framework

Table A.1 Outcome Framework: Outcomes, Indicators, Suggested Measures and Service Focus (taken from Fischer et al. 2022).

Dimension	Outcome	Indicator	Suggested Measures	Focus
1. Reduced Stigma Family and friends feel comfortable seeking help, from a reliable source 1.1 Early help-seeking 1.2 Positive experien with delivered servic and no experience of stigma from engagement with information and/or support services 1.2 Positive experien with delivered servic and no experience of stigma from engagement with information and/or support services 1.3 Accreditation bac to an accepted Natio Quality Framework Standard is visible or website, physical location, informatior	1. Reduced	1.1 Early help-seeking	 Help-seeking Examples: Reasons for help seeking and understanding previous attempts at help seeking (and whether they waited for help) Proportion changes in earlier help seeking reasons (e.g. from crisis to information/ earlier help seeking identified) Number and demographic characteristics of family and friends seeking help (e.g. sex, age group, identify as Aboriginal and/or Torres Strait Islander peoples, identify as requiring culturally specific or diverse information, locality) 	Family and Friends
	engagement with information and/or	Client-reported experiences Examples: Client Satisfaction Questionnaire (CSQ-8) Outcome or Session Rating Scale (ORS + SRS) Treatment Perception Questionnaire (TPQ) PREM for Addiction Treatment (PREMAT) Your Experience Survey PHN Survey (YES PHN Survey) Consumer Assessment of Behaviour Health Services Institute (CABHSI) Modified Patient Feedback	Family and Friends	
		Standard is visible on website, physical location, information and support services	 Program and organisation documentation Example: Program and organisation documentation supporting implementation of National Quality Framework and its principles 	Organisation
2. Increased Awareness	Family and friends are aware of available information and support services, and can obtain knowledge	2.1 Awareness of existing information and support services	 Awareness of services Examples: Demographic information (as per 1.1) Increase in awareness of available information and support services from presurvey to follow-up evaluation 	Family and Friends

Dimension	Outcome	Indicator	Suggested Measures	Focus
	of the effects and impact of substance use in culturally safe and appropriate ways		 How participants heard about information and support services (e.g. from another client, via website) Awareness of other information and support services, e.g. family and intimate partner violence services (unprompted and prompted) 	
		2.2 Adequate knowledge of basic AOD use and treatment	 AOD use and treatment knowledge Examples: Demographic information (as per 1.1) Participant numbers Pre and post testing of workshop/education learning outcomes which have been informed by the established evidence base Pre and post testing of understanding specific harms and risks associated with AOD use informed by the established evidence base 	Family and Friends
	2.3 Increased awareness of how to support a family member or friends with their AOD use	 Supporting awareness Examples: Pre and post testing of workshop/education learning outcomes Pre and post testing of workshop/education content Client surveys and feedback Documenting client stories Staff feedback Family sensitive workforce development activities, inclusive of peers and volunteers 	Family and Friends Information and Support Services Workforce (including peers and volunteers)	
Acquisition for Wellbeingable to acquire skills and tools that enhance their quality of life in culturally safe and appropriate wayslife a.2 ski3.2 3.3	 3.1 Enhanced quality of life 3.2 Improved coping skills 3.3 Reduced psychological distress 	 Client-reported outcomes Examples: Quality of life - World Health Organization Quality of Life assessment (WHOQOLBREF) Coping - Coping Questionnaire (CQ); Hopefulness-Hopelessness Scale (HOPE) Psychological distress - K10 Psychological Distress Scale; Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) Aboriginal and Torres Strait Islander peoples specific - Aboriginal Resilience and Recovery Questionnaire (ARRQ), Here and Now Aboriginal Assessment, Strong Souls: Social and Emotional Wellbeing Assessment Tool 	Family and Friends	
		Skill assessments Examples: • Demographic information (as per 1.1) • Participant numbers	Family and Friends Information and Support Services	

Dimension	Outcome	Indicator	Suggested Measures	Focus
			 Pre and post testing of learning outcomes Pre and post testing of workshop content Client feedback Documenting client stories Examples: Staff, including peers and volunteers' feedback Family sensitive workforce development activities, inclusive of peers and volunteers, assessing: participant numbers, pre and post testing of learning outcomes, pre and post testing of workshop content, client feedback 	Workforce (including peers and volunteers)
Accessibility access established, reliable referral pathways, across the treatment continuum support are pro- multiple formation 4.2 Culturally sa inclusive suppor services 4.2 Culturally sa inclusive suppor services 4.3 Partnerships	4.1 Information and support are provided in multiple formats	 Program and organisation documentation Examples: Routine record keeping (asking and recording number of family and friends e.g. website analytics including visits, page views, time per page) Gap analysis of specific information and support service elements Number of resources available in languages other than English, and accuracy Number of information and support services available in multiple formats 	Information and Support Services	
	4.2 Culturally safe and inclusive support services	 Program and organisation documentation Examples: Cultural Safety in Health Care for Indigenous Australians: Monitoring Framework measures Organisational audits (e.g. NADA's Family Inclusive Practice Audit; NADA's Tools for Change: a new way of working with families and carers; ADF's Power of Words) Staff surveys, workforce development initiatives (including number of peer family and friend workers recruited and retained) Client feedback and complaints Gap analysis of specific service elements, such as translated materials or materials/ services that cater to people with specific cultural identities/needs 	Information and Support Services	
			 Program and organisation documentation Examples: Records of activities undertaken to maintain and enhance partnerships and collaborations (e.g. meetings held, memoranda of understanding signed, events co-hosted) Proportion of referrals to external information and support services is appropriate 	Information and Support Services

Dimension	Outcome	Indicator	Suggested Measures	Focus
			 Family and friends are actively supported to engage with information and support services that meet their AOD-related and non-AOD needs and goals 	
5. Quality Improvement	Organisations consistently demonstrate that they meet acceptable levels of quality in the delivery of information and support services to family and friends	 5.1 Accreditation maintained to a Standard accepted by the National Quality Framework 5.2 Legislative compliance 	 Program and organisation documentation supporting implementation of National Quality Framework and its principles. Examples: Records of current accreditation to relevant standards Records on development and implementation adherence to the established evidence base Documentation demonstrating progress/ adherence to National Quality Framework principles, i.e.: organisational governance, clinical governance, planning and engagement, collaboration and partnerships, workforce development, information systems compliance, continuous improvement, health and safety 	Information and Support Services

Appendix II: Family-Based Treatments

Description			
Widely used approach to family-based AOD treatment, and many families can improve their functioning and dynamics simply by learning about AOD addiction and recovery			
Has good empirical support for reducing AOD use, especially among adolescents. It addresses individual behaviours and family processes. It has improved functioning among adolescents, parents, families, and families' relationships within their communities			
These approaches help support recovery by teaching clients to improve the quality of their relationships, engage in healthier communication, and build positive relationships with one another			
Uses a problem-focused, practical approach to reduce or eliminate youth substance misuse and enhance family functioning			
Also takes a problem-solving approach to engaging, motivating, and creating behaviour change among clients. Families are also taught how to apply their newfound skills to future situations			
Invites families to build a positive vision of their future and identify interpersonal changes and improvements in target behaviours needed to make that vision a reality			
Uses a combination of individual and group therapy approaches and involves members of the client's network of supportive family members and friends in sessions. The main goal is for members of the supportive network to learn how they can reinforce the client's efforts to achieve and maintain abstinence			
Intensive family therapy approach that seeks to alter environmental influences associated with an adolescent's serious clinical problems, Uses goal oriented and family strengthening strategies			
Combines elements of systemic family therapy and motivational interviewing (MI)			
Structured, family-focused approach that assumes environmental contingencies are important in promoting treatment entry			

Table A2. Description of Family Based Treatments (SAMHSA, 2020)