

An Outcomes Framework for Family and Friends

Consultation Paper

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Stakeholder consultation

This consultation paper aims to promote stakeholder engagement and input into the development of a Family and Friends Outcomes Framework for AOD services.

Stakeholder input is particularly sought on three key issues in the development of a Family and Friends Outcomes Framework:

- *What does high quality AOD service delivery to family and friends look like?*
 - i.e., what outcomes (benefits, positive changes) should be the goal of service delivery to family and friends?
- *What activities or results show progress towards/achievement of high quality AOD service?*
 - i.e., what specific indicators can be used to monitor and assess these outcomes?
- *How can information about these results or activities be collected?*
 - i.e., what information and data should be collected to measure/assess these indicators?

Please see **5.1 Stakeholder** input (p. 17) for more detailed consultation questions

Please email submissions to ncetaconsultation@flinders.edu.au by 21 January 2021

*Please attach **cover page** so we can document the stakeholder consultation process*

This consultation paper is also available to download from the NCETA website

<https://nceta.flinders.edu.au/stakeholder-consultations>

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1. Introduction

1.1 Purpose of this consultation paper

This consultation paper is designed to support and guide stakeholder input into the development of a Family and Friends Outcome Framework for Alcohol and other Drug (AOD) services. The aim is to develop a framework that is informed by the needs, priorities and capacity of the AOD sector, including service providers, families, clients and other stakeholders.

An outcomes framework is a resource designed to guide the identification and assessment of the outcomes of a program, service, policy or other activity.

The Family and Friends Outcomes Framework will be a practical resource that:

- Supports AOD services to develop a greater understanding of current service quality
- Provides AOD services with a set of standards to measure quality of service delivery and outcomes
- Offers the sector a set of common metrics that can be used to track the quality and success of delivery across services over time and allow for benchmarking
- Supports the integration of customer satisfaction as a key marker of service quality and success.

This consultation paper summarises key ideas and research on:

- Defining and identifying outcomes for information and service providers to families and friends
- The purpose and benefits of outcomes frameworks in service provision
- Existing research on the information and support needs of family and friends (to inform identification of outcomes within the Framework)
- Existing measures of families' experience of health and welfare services (to inform development of measures within the Framework).

Stakeholder input is particularly sought on three key issues in the development of a Family and Friends Outcomes Framework:

- *What does high quality AOD service delivery to family and friends look like?*
 - i.e., what outcomes (benefits, positive changes) should be the goal of service delivery to family and friends?
- *What activities or results show progress towards/achievement of high quality AOD service?*
 - i.e., what specific indicators can be used to monitor and assess these outcomes?
- *How can information about these results or activities be collected?*
 - i.e., what information/data should be collected to measure/assess these indicators?

Please see **5.1 Stakeholder** input (p. 17) for more detailed consultation questions

1.2 Background and context

Families and friends are a major source of support for people experiencing alcohol and/or other drug (AOD) issues and are often significantly impacted with the consequential harms associated with dealing or living with a loved one with AOD issues [1-3]. However, family and friends often lack the required assistance, confidence and knowledge of how to respond effectively to support their family member or friend [2, 4]. Further, social stigma and self-blame are major barriers in seeking the help they need to assist their affected family member or friend [5].

It is crucial that concerned family and friends are equipped with the necessary confidence and skills to assist in their family member or friend's recovery, and seek help and guidance as early as possible before problems become more chronic and recovery more challenging [6]. Family and friends also need support to protect their own wellbeing which is often compromised when dealing with their loved one's problematic AOD issues [1, 2, 7].

At the time of writing, Australia has limited information and support services for families and friends of people with a substance use disorder, or for those who are concerned about alcohol and/or drug use of their family member or friend [8]. This is an important gap in service delivery which can contribute to barriers to accessing help for both the person in need and for family members who may be experiencing significant disruptions to family cohesion and daily life.

In June 2021 the Department of Health commissioned the Alcohol and Drug Foundation (ADF), via the National Drug and Alcohol Program, to reduce the impact of AOD misuse to individuals, families and communities. One of the intended outcomes of the National Drug and Alcohol Program is to achieve improved health and social outcomes for individuals, families, and communities at risk of, or currently affected by, substance misuse in Australia. The ADF Information and Support (ISS) Program for Family and Friends forms part of the Drug and Alcohol Program's funded work.

The ADF ISS program involves a range of activities including:

- Funding for capacity building and research projects
- Development of a digital portal that provides high quality, accurate and personalised information and support to meet the needs of family and friends ([Path2Help](#)), and
- The current outcomes framework to guide and support AOD services to assess the quality and outcomes of service delivery to family and friends.

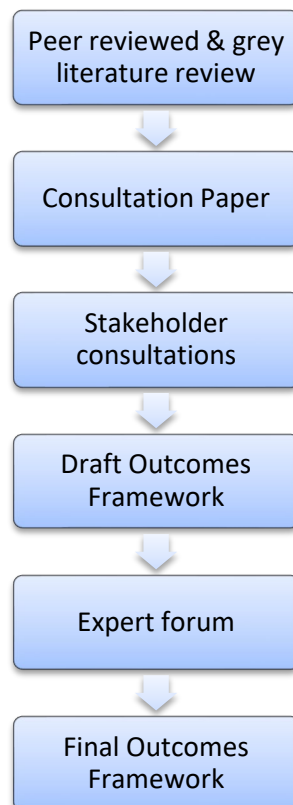
The development of a Family and Friends Outcomes Framework is the focus of this consultation paper.

1.3 Developing a Family and Friends Outcomes Framework

The key purpose of this Family and Friends Outcomes Framework is to create a standard set of outcomes that can be systematically measured for evaluation and research purposes. It will also allow for benchmarking and quality improvement initiatives. It is envisaged that the Outcomes Framework will enable service providers to collect better quality data which will strengthen and support capacity to engage in evaluation of programs and services. In doing so, services will be able to develop more robust funding proposals that show the benefits to program participants, funders and other stakeholders.

The development of an Outcomes Framework will integrate information and insights from peer reviewed research, the non-peer-reviewed 'grey literature' in this area and stakeholder consultation. Figure 1 provides an overview of this process. This consultation paper is designed to support and promote stakeholder input and guidance on developing the Framework. Written submissions are welcome. Interviews/focus groups with key informants who have particular expertise in this area will also be conducted. Drawing on the research evidence and stakeholder input a draft Family and Friends Outcomes Framework will be developed. This draft Framework will undergo further review and refinement by an expert forum of invited key informants, which will guide the development of the final Framework.

Figure 1 Overview of Family Outcomes Framework development process



2. Key concepts

This section summarises key concepts related to outcomes frameworks in general, including the definition of outcomes and the purpose and structure of outcomes frameworks.

2.1 Outcomes

Outcomes are the changes or benefits that are intended to result from the delivery of a particular service, program or policy [9, 10]. Outcomes can be short term, medium term or longer term [9]. For example, for a smoking cessation program short term outcomes may include an increase in participants' knowledge and confidence in relation to coping techniques to manage cravings, a medium term outcome (e.g., 6 months) could be the number or proportion of participants who have reduced or stopped smoking and a long term outcome (e.g., 12 months) could be the number or proportion of participants who have maintained their smoking cessation (or reduction).

Within health and human services, outcomes generally address three broad areas [10]:

1. Knowledge/learnings/attitudes
2. Behaviours (e.g., reduction in undesirable behaviours, increase in desirable behaviours, continuation of new behaviour)
3. Condition/status (e.g., improvement in social relationships, positive change in financial circumstances, improvement in health indicator).

These outcomes address change and improvement at the person (client) level. Outcomes may also address results at a program level (e.g., participant satisfaction), organisation level (e.g., financial) or community level (e.g., public health) [10].

2.2 Outcomes frameworks

An outcomes framework is a resource designed to guide the identification and assessment of the outcomes of a program, service, policy or other activity [10]. Outcomes frameworks are commonly designed as a resource for a particular community of practitioners to guide and support service planning, delivery and assessment. The aim is to support organisations to achieve the intended aims and objectives of services and programs [9]. Governments in Australia and other similar countries (e.g., the UK, USA) are increasingly emphasising the importance of demonstrating links between funding for programs or services and tangible results (i.e., outcomes) for the community.

Outcomes frameworks usually contain a set of components that range from very broad vision or aim to very concrete and specific measures of activities or results. An outcomes framework will present

these components in a coherent chain of logic to clearly demonstrate the links between the aim or vision of the program and how it is to be assessed.

Outcomes frameworks usually include [9-11]:

- Vision: High-level vision to be realised/issue to be addressed/impact to be demonstrated
- Outcomes: Benefits or positive changes to be achieved, or progressed towards in the short, medium and longer term
- Indicators: Specific results that signify a change has occurred on a particular outcome
- Measures: Data or information that can be used to assess progress against each indicator.

Example

Disability Housing– Building a Common Outcomes Framework for People with Disability

<https://disabilityhousingoutcomes.com/>

Social Ventures Australia (SVA) Consulting [12]

SVA Consulting developed a disability housing outcomes framework in partnership with key stakeholders from the sector.

The Framework identified six outcomes which ‘reflect core values of choice and control, and what matters most for people with disability to live a good life’:

1. Daily living: people with disability are in control of their daily living routines
2. Health: people with disability are physically, mentally and emotionally healthy and can access health services
3. Relationships and community: people with disability have healthy relationships at home and are connected with their community
4. Rights and voice: people with disability can exercise their rights and responsibilities, and have valued roles in the community
5. Independence: people with disability have choice and control over decisions about their lives
6. Stability and safety: people with disability are comfortable in their home and safe from physical and psychological harm.

Eight indicators were identified to assess progress towards these outcomes, including self-report and independent observations (e.g., staff observations).

For example, for the ‘health’ outcome:

- Two priority indicators were identified: satisfaction with access to health services and change in healthier habits
- Service satisfaction was measured by self-report (resident or family interview/survey)
- Change in healthier habits was measured by staff records.

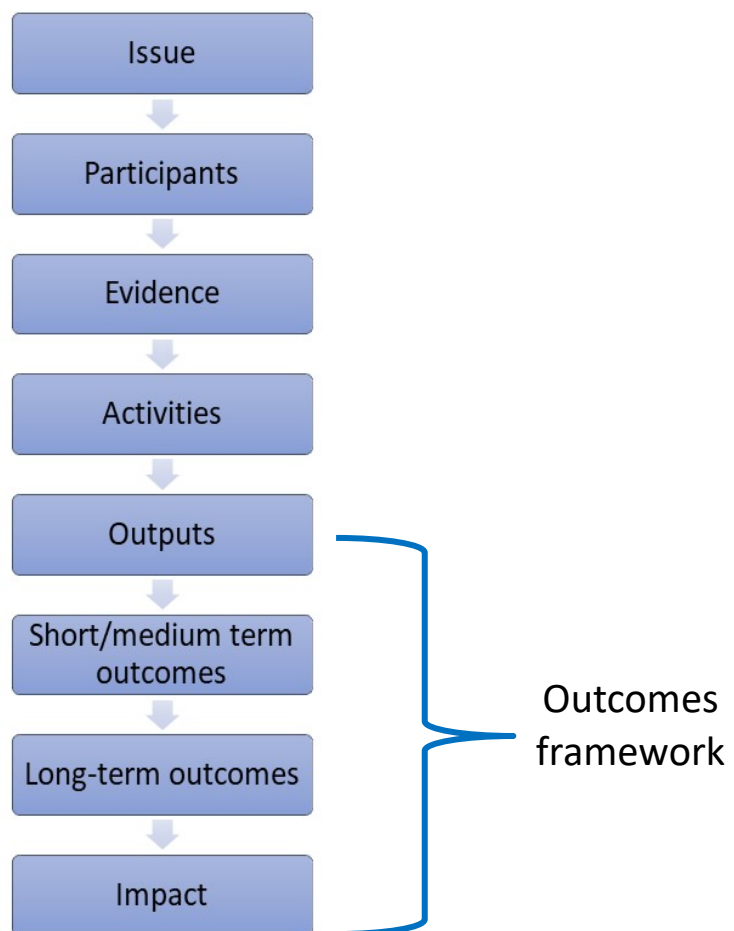
2.3 Benefits of outcomes frameworks

Outcomes frameworks are designed to support organisations' capacity and effectiveness in achieving the results and benefits that reflect their core business – 'our reason for being here'. An outcomes framework offers a clear and simple logic scaffolding that supports organisations to reflect on the links between [9]:

- What outcomes (changes, improvements, benefits) are we aiming to achieve?
- How will we know we have achieved these outcomes (or are making progress)?

There are various approaches to developing outcomes models and frameworks [11]. This consultation paper uses a program logic approach, which is familiar to most organisations. Program logic models demonstrate the links in a causal chain between the identification of an issue or problem, the program or activity designed to address this issue and the outcomes and impact of the program or activity. An example of a program logic model is provided in Figure 2 [9, 13].

Figure 2 Outcomes framework within a program logic model



As with program logic models in general, one of the main benefits of an outcomes framework is to support organisations to apply a systematic approach to demonstrating how a program or activity has achieved a particular result or benefit. Implementing an outcomes framework can provide valuable input into an organisations' continual improvement processes and support the development of compelling evidence to funders and other stakeholders regarding the benefits of a particular program or service.

Most AOD services have systems and processes in place to assess quality, performance, impact and other aspects of organisational functioning across a range of areas. Some AOD services may have processes in place for assessing family outcomes related to their service delivery, whereas other organisations may not prioritise family outcomes within their suite of outcome assessments. A common approach to assessing family outcomes that is provided by an outcomes framework offers benefits and advantages to all AOD services, including those with established assessment in this area.

Key benefits of outcomes frameworks include [9](#), [14](#)]:

- Reducing time and cost for individual organisations to research and develop a comprehensive approach to identifying and assessing outcomes in a particular area
- Opportunity for organisations to apply a shared outcomes framework 'as is', or use as a starting point to develop their own customised approach
- Improving the quality of outcomes assessment by providing access to evidence-based resources
- Opportunity for organisations to compare their established approach to assessment with an independently developed framework
 - For example, new outcomes, indicators or measures may be added to an established approach to assessing family outcomes
- Enabling organisations and funders to compare 'like with like' across programs or organisations delivering services in comparable areas.

It is also important to acknowledge that an outcomes focused approach has limitations and may not address all aspects of service quality and effectiveness [\[15, 16\]](#). For example, all data sources and measures have some weaknesses or limitations in relation to sensitivity and specificity of assessment. Some aspects of care are difficult to capture within an outcomes framework, for example a unique capacity or approach of a service or team that may not be reflected in standardised measures [\[15\]](#). Including both process and outcome indicators and measures is recommended to reflect the complexity of service delivery and the factors that influence the demonstration of desired outcomes.

Furthermore, in complex areas such as health and other outcomes, a range of factors external to a service can impact on the outcomes that are achieved with particular participants (e.g., an individual's life circumstances, lifestyle, socio-economic status) [15-17]. There may also be considerable time delays in the full realisation of the relationship between service delivery and the impact on participants wellbeing and daily life, which may extend beyond feasible timeframes for data collection [15, 16].

In sum, outcomes frameworks are useful tools to guide and support services to engage in continuous quality improvement and produce high quality evidence on the achievement of outcomes and benefits for participants. The complexities and nuances outlined above indicate that outcomes frameworks are best implemented and interpreted in combination with insights from practitioners' clinical, management and service delivery experience [15].

The first step in developing an Outcomes Framework for Family and Friends is to understand the service experiences and outcomes that are most relevant and meaningful for family and friends. The next section summarises key insights from the peer reviewed and 'grey' (non-peer reviewed) literature, drawing on research commissioned by the ADF and other sources.

3. Existing research – service needs of family and friends

Family and friends are usually the main sources of support for people with alcohol or drug (AOD) issues. However, they are often at a loss on how and where to seek accurate information and assistance to help their loved ones [7, 18]. Parents or guardians are most likely to seek information and support [19]. In 2020, the ADF conducted a nationally representative survey of 510 adults who were concerned about a family member or friend's AOD use. More than 70% of survey respondents who needed relevant information and support did not immediately seek help, with more than a third of survey respondents only seeking support when their family member or friend was perceived to be of high risk. In a recent study of 90 affected family members, over three-quarters of participants had not received any assistance from AOD services [2]. There is also a lack of clear pathways in providing family and friends the support and guidance they require for their particular needs [20]. These findings indicate there is a significant unmet need in service provision to family and friends.

Family and friends can experience significant strain and disruption in their daily lives as a result of a family member or friend's alcohol or drug use. Affected family members often experience mental, emotional, physical, financial, and social hardships due to the strain of having a family member who has AOD issues [1, 2, 4, 5, 20]. These include reduced quality of life and social adjustment problems, with these risks higher for women, those whose family member or friend has more problematic AOD use and those who are from lower socio-economic backgrounds [1, 2, 21]. These negative

repercussions for family members may also adversely impact the recovery process of their affected relative [2, 5].

At the time of writing, however, Australia has limited information and support services that are specifically catered for concerned families and friends, which may further add to negative outcomes for family members [4]. There is a clear need for concerned family members and friends to have timely, accessible and appropriate information and support to help themselves and their affected family member or friend [2, 4, 20].

One of the key outcomes of the broader ADF ISS project within which the current Outcomes Framework sits, is the development of a digital portal ([Path2Help](#)). This portal includes a rapid assessment tool which curates the most personally relevant information and support services for portal users.

3.1 Information and support needs of family and friends

Information and support needs of concerned family and friends are likely to differ depending on their circumstances, including their current and past coping strategies and help seeking actions. For example, a recent ADF commissioned nationally representative survey indicated that family and friends who have not yet sought support are likely to seek information on ways to communicate with their family member or friend, and strategies to support their loved one to seek assistance [6]. Those who have already sought support are more likely to seek relevant and up-to-date information about drug/alcohol use and signs of addiction [6]. Consistent with the observations from the ADF national survey, other research has found that the greatest needs reported by concerned family and friends relate to learning how best to provide support and have conversations with their affected family member or friend, and strategies for managing conflict and setting boundaries [19, 21, 22]. Groups such as Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse (CALD) communities may have additional or differing needs. Research commissioned by the ADF indicates that Aboriginal and Torres Strait Islander family and friends prefer in-person conversations with someone knowledgeable that they respect in a comfortable and relaxed environment. Accessing information online was considered less useful. Aboriginal and Torres Strait Islander family and friends also report difficulties in finding accurate, clear and culturally relevant information online that is suited to their needs. Similarly, for CALD communities, translated resources are often inappropriate, with accuracy and importance often lost in translation [23]. There is a clear need for culturally appropriate resources tailored to meet specific cultural groups' needs [24]. These information and support resources also need to address cultural taboos related to drug and alcohol use within particular communities.

Improvements to information and support services to family and friends should include the provision of a wider range of information, resources and supports offered across different mediums [8]. Options include hard copy materials and downloadable electronic documents which can be accessed at people's convenience and discretion [24]. Web-based and tele-based support services are also important for people in geographically distanced areas and for those who prefer anonymity/privacy [25].

Online delivery of education and support programs have additional benefits: 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 [26]. For people with low literacy levels, other resources such as audio or visual (e.g., podcasts, videos, DVDs) may be beneficial. 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 [21, 27].

Whilst online information and resources are an important and useful option for concerned family and friends, it is worth noting that ADF commissioned research indicates a strong preference for face-to-face counselling by family and friends [19], especially for people from Aboriginal and Torres Strait Islander communities [23]. Meeting this need presents a challenge to AOD services due to a lack of capacity and funding to provide intensive support to families such as case management and referrals to other services.

3.2 Barriers to accessing information and support

A range of barriers and challenges have been identified that concerned family and friends may experience when seeking access to information and support. Common barriers identified in research commissioned by the ADF and the broader research literature include [1, 3, 4, 21-23]:

- 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.

Three barriers have been particularly highlighted in the research literature. Stigma, shame and self-blame often cause affected family members to socially isolate in an effort to keep the 'shameful' problem a secret [4, 7, 21]. Family members are often hesitant to share their difficulties with others as a result of actual or perceived stigma, and can fear being judged or blamed [5, 22]. These psychosocial barriers may diminish their willingness to seek out information and support they require [5] [1].

Second, lack of knowledge and awareness of where to seek help and support has been identified as a common and significant barrier to help seeking for concerned family and friends [5, 19]. This includes online resources. In a national study on AOD-focused websites, almost half of the 1214 website users surveyed were unable to easily access information they wanted and reported taking as long as 15 minutes to locate desired information [28].

Third, access to in-person support can be problematic. Prolonged wait times for appointments can result in some families being unable to access support when it is most required [19, 22]. Affected family members are often financially impacted by the associated costs of their loved one's drug use issues (e.g., treatment costs, legal debts) [2, 4]. Costs of support services can discourage family members from seeking help for themselves, and this is especially the case for lower income families [1, 3].

Addressing stigma as a barrier to help seeking

Stigma has been identified as a particularly significant barrier to help seeking from family and friends, which may contribute to delays in accessing information and support, or difficulties in engaging with services [1, 4, 20]. There are various dimensions to the feelings of stigma that family members and friends may experience [5]. These include public stigma (negative public attitudes towards drug and alcohol use), self-stigma (internalisation of public stigma resulting in reduced self-esteem) and stigma by association (experience of shame and self-blame as a result of their family member's problematic AOD use) [5, 29] [ENREF 28](#). Stigma by association can result in a loss of respect and status for the affected family member within their social circle and the wider public [22]. It is also important to recognise that attitudes and beliefs about AOD use vary across ethnic and/or religious cultures. These diverse perspectives need to be taken into account when considering how stigma can be addressed within cultural boundaries in order to effectively support help seeking by concerned family and friends [23].

Confidentiality and privacy are crucial considerations in relation to managing stigma as a barrier to help seeking. Information and counselling services via telephone or online enable access to support whilst preserving anonymity and privacy [21, 26] [ENREF 24](#). For face-to-face appointments, continual assurance and reminders that privacy and confidentiality will be maintained can help allay

privacy concerns. Other online resources, such as videos on social media platforms or downloadable resource materials, also enable family and friends to access crucial information whilst maintaining anonymity [23].

4. Existing family outcomes frameworks

As part of the review of existing work in the peer-reviewed and 'grey' literatures, a comprehensive search was conducted of the Australian and international literature to identify and review existing family outcomes frameworks. No existing frameworks were identified which were primarily focused on outcomes for family and friends of adults receiving health and welfare services.

The family outcomes frameworks that were identified were mainly focused on:

- Children and/or youth
- Outcomes related to the welfare and wellbeing of children and youth (e.g., school attendance, mental health)
- The experiences of children and/or parents/guardians receiving health and welfare services.

Examples of outcomes frameworks in health and human services include the NSW Human Services Outcomes Framework [30], the Child Development Council's Outcomes Framework for Children and Young People (SA) [31] and the Western Australia Primary Health Alliance (WAPHA) Outcomes Framework [32]. Appendix A lists additional examples of Outcomes Frameworks focused on family outcomes from the child and youth health and welfare sectors.

Stakeholder input on other relevant family outcomes frameworks is welcome

5. Towards a Family and Friends Outcomes Framework for AOD services

Previous sections in this consultation paper overviewed outcomes frameworks and their application in health and human services, and outlined key findings from existing research on the service needs of family and friends concerned about a loved one's alcohol or drug use. Drawing on this review of existing work, this section is focused on the next steps in developing a Family and Friends Outcomes Framework. Specifically, this section presents:

- An example of a Family and Friends Outcomes Framework (drawing on the previous review)
- Examples of relevant outcome measures from the peer reviewed research and 'grey' literatures.

As reviewed earlier, the ADF Information and Support (ISS) Program for Family and Friends aims to improve service delivery to family and friends who are concerned about the AOD use of a family member or friend. Specifically, the ISS Program aims to improve concerned family and friends' knowledge of, and access to, high quality evidence-based approaches to meet their information and support needs. In addition, the program aims to reduce stigma-related barriers that discourage family and friends from accessing information and support. The aim of the Family and Friends Outcomes Framework is to support AOD services to achieve these positive outcomes for concerned family and friends of people who use alcohol or other drugs.

Figure 3 provides an example of key elements in a Family and Friends Outcomes Framework that link with the aims of the ADF ISS program. This example is designed to show the relationship between the major elements of a Family and Friends Outcomes Framework for AOD services, and to demonstrate the types of information that will be included in each of the elements of the Framework.

5.1 Stakeholder input

Stakeholder input and guidance is sought on all aspects of the Family and Friends Outcomes Framework that is under development.

Stakeholder input is invited on:

- The overall **structure** of the Framework
 - *Does the example in Figure 3 serve as a good model for developing a Family and Friends Outcomes Framework for the sector? How can model this be improved?*
- The overall **aim/vision** of the Framework
 - *What does high quality service delivery to concerned family and friends look like? How can this be represented in a statement of vision/aims?*
- The **outcomes** that represent the specific benefits/positive changes resulting from high quality service delivery
 - *What specific outcomes should be identified for the Framework that define high quality service delivery to concerned family and friends?*
- The **indicators** that can be used to monitor and assess these outcomes
 - *What activities, or results can be used to assess progress towards, or achievement of these outcomes?*
- The **measures** that can be used to collect information about these indicators
 - *What types of data and information could be collected on these indicators? Can an agreed set of measures be identified to support consistency of measurement across services?*
 - ***Please note: Table 1 (page 22) provides examples of family-focused outcome measures that could be adapted for inclusion in the current framework***
- The **value and feasibility** of developing a set of indicators and measures that could be used for benchmarking across services.

Figure 3 Example of a Family and Friends Outcomes Framework



Outcomes framework for family and friends



6. Measures – review of existing relevant tools

This section summarises the findings of a comprehensive search undertaken of the peer reviewed and ‘grey’ (non-peer reviewed) research literatures to identify outcome measures that align with the aims of the ADF ISS Program regarding:

- Family and friends’ knowledge of, and access to, information and support that meets their needs
- Stigma-related barriers that discourage family and friends from help seeking.

This search did not identify any existing measures that reflected the same context of the proposed Family and Friends Outcomes Framework (i.e., concerned family or friends of people experiencing alcohol and/or other drug concerns).

This section provides an overview of related and relevant tools that could be used to inform the development of measures for the proposed Family and Friends Outcomes Framework.

Two major sources of information and data which could be used to measure progress towards, or achievement of, outcomes are considered here: organisational data and self-report data. Collating information from different and independent sources is a well-established approach to strengthening the accuracy and validity of assessment in any context.

Stakeholder input on established outcomes measures of relevance to the current project is welcome

6.1 Organisational data sources

There are considerable time and cost benefits to using existing data collected within standard organisational processes. As outlined in Figure 3, organisational data could include information such as counts of actual information sources or support services provided (e.g., number of resources available, number of counselling sessions delivered). Utility and access measures could include data such as number and length of website visits, number of downloads/views of resources or number of participants who engaged in a program (including retention rate).

The use of organisational data to assess services and programs may be familiar to many stakeholders. The purpose of the current consultation is to seek stakeholder input on the particular types of organisational data that would be most useful and feasible to incorporate into the current Framework.

6.2 Self-report measures – families’ experience of service

Stakeholder input on established self-report measures of relevance to the current project is welcome

A comprehensive search of the peer reviewed research literature was conducted to identify established and validated scales addressing families’ service needs and experiences, and the experience of stigma in relation to a loved one’s alcohol or drug use.

The following databases were searched for peer-reviewed articles containing self-report survey measures: Medline (Ovid), PsychINFO (Ovid), Emcare (Ovid), CINAHL (EBSCO), Scopus (Elsevier), Cochrane (Wiley), ProQuest and Web of Science (Clarivate Analytics), Google Scholar.

In relation to service needs and experiences, the search terms "family" OR "friends" were combined with: "outcomes framework" AND "information OR support" AND "assessment OR measures"; service “delivery OR accessibility OR quality OR availability”. A total of 1,662 peer reviewed articles were identified, which was then limited to 127 articles that used survey or questionnaire measures. A review of these 127 articles identified 11 self-report measures of service needs and experiences of relevance to the current project.

As observed previously in relation to existing family outcomes frameworks, self-report measures of families’ experience of service quality have primarily been developed to assess parents’ or guardians’ experience of child or youth health and welfare services. No self-report measures were identified in the peer reviewed literature which addressed concerned family and friends’ experiences of seeking information and support from AOD or other services.

Table 1 provides an overview of the 11 measures identified in the peer-reviewed literature, including a list of the most relevant survey items (where licencing allows), evaluations (if any) of psychometric properties and notes regarding respondents for whom the measures are designed and any requirements for use (e.g., permissions, licencing).

In sum, the measures presented in Table 1:

- Are developed to assess the views and experiences of parents/guardians/carers of children or youth receiving health or welfare services
- Focus on parents/guardians/carers views and experiences of service:
 - Availability/accessibility and adequacy
 - Quality (e.g., meet needs) and effectiveness (i.e., made a difference)
 - Professionalism (e.g., friendly, supportive)
 - Cultural sensitivity
- Include general ratings of satisfaction with service.

6.3 Self-report measures – families’ experience of stigma

The following databases were searched for peer-reviewed articles containing self-report survey measures on secondary stigma experienced by families and friends: PubMed, PsychINFO (Ovid), Scopus (Elsevier) and Google Scholar. The following search terms were used: “substance use” OR “addiction” OR “drugs” OR “alcohol” AND "family" OR "friends" OR “caregiver” combined with: "stigma" OR “shame” OR “embarrassment" AND “measures” OR “scales” OR “assessment”. Over 11,300 articles were identified, the majority of which focused on self-stigma of people who use alcohol or other drugs. Table 2 presents three measures identified in the peer-reviewed literature that may be suitable for assessing stigma experienced by family members or friends that are particularly relevant to the context of the current framework. Only one stigma measure was identified that is specifically tailored for caregivers of AOD users [33].

Limitations of example self-report measures (Tables 1 and 2)

It is acknowledged that none of the measures listed in Table 1 are appropriate or suitable to be incorporated into the proposed Framework as they are currently developed. These measures are presented to facilitate and support stakeholder input into the types of self-report measures that could be considered for inclusion in the proposed Framework.

In the context of the current project, limitations of the measures in Table 1 include survey length (time/effort burden for respondents), survey context (services delivered to children or youth), limited psychometric evaluation (for some measures) and lack of assessment for cultural safety. Similarly, the main limitation of the scales presented in Table 2 is that most are not designed to be used with concerned family and friends. The measures have also not been as extensively used in the AOD research literature, hence their validity and reliability in the current context has not been established. Hence the measures in Tables 1 and 2 are presented for example purposes only, with stakeholder input sought on whether particular measures or specific items could be adapted to suit the aims and context of the current project.

It is acknowledged that adapting or modifying existing survey instruments is not preferred, as this approach effectively nullifies existing evidence on the psychometric properties of the original scale. Unfortunately, the search of the peer-reviewed and grey literatures did not identify any established measures that could be used in the proposed Framework without modification or adaptation.

Drawing on the measures summarised in Tables 1 and 2, stakeholder input is sought on the types of self-report measures that would be most useful and feasible to incorporate into the proposed Framework. This may include identification of survey topics or items from measures listed in Tables 1 and 2 that could be adapted to suit the current framework.

Table 1 Examples of family focused outcome measures

Note. Item number may differ from order of items in original instrument (items sorted by domain measured for ease of review).

	Measure	Items	Psychometric properties	Notes
1	<p>Mental Health Carer Experience Survey [34] [sample copy]</p> <p>Australian Mental Health Outcomes and Classification Network</p>	<p>Making a difference <i>As a result of your experience with this mental health service in the last three months, has your life changed in the following areas?</i></p> <ol style="list-style-type: none"> 1. Your relationship with the person for whom you care 2. Your hopefulness for your future 3. Your overall wellbeing 4. Overall, how would you rate your experience as a carer with this mental health service over the last three months? Response scale: 1 (poor), 2 (fair), 3 (good), 4 (very good), 5 (excellent) and 6 (don't know) <p><i>As a carer with a family member, partner or friend who had contact with this mental health service in the last three months, how often did the following occur/were you given the following?</i></p> <p>Providing information and support</p> <ol style="list-style-type: none"> 5. You understood what you could expect from the mental health service for yourself and your family member, partner or friend 6. You were given an explanation of any legal issues that might affect your family member, partner or friend 7. You understood your rights and responsibilities 8. You were given information about services and strategies available if your family member, partner or friend became unwell again 9. A brochure or other material about your rights and responsibilities 10. An explanation of how to make a compliment or complaint about the mental health service 11. Information about carer support services such as local groups, carer consultants, counsellors) 12. Information on opportunities to participate in improving this mental health service 13. A number you could call after hours for the service 14. Information about taking a support person to meetings or hearings if you wished <p>Valuing individuality</p> <ol style="list-style-type: none"> 15. Your personal values, beliefs and circumstances were taken into consideration 16. You were able to obtain cultural or language support (such as an interpreter) when you needed 17. You were given the opportunity to enhance your abilities as a carer 18. Staff worked in a way that supported your relationship with your family member, partner or friend 	No information found	<p>Respondents: Carers (i.e., family members, partners or friends) of those who access mental health services</p> <p>License required for use (no cost): https://www.amhocn.org/mental-health-carer-experience-survey-0</p> <p>Instrument: https://www.amhocn.org/publications/mental-health-carer-experience-survey</p>

	Measure	Items	Psychometric properties	Notes
		<p>Supporting active participation</p> <p>19. You were given the opportunity to provide relevant information about your family member, partner or friend</p> <p>20. You were involved in decisions affecting your family member, partner or friend</p> <p>21. You were given opportunities to discuss the care, treatment and recovery of your family member, partner or friend (even, if for reasons of confidentiality, you could not be told specific information)</p> <p>22. You were involved in planning for the ongoing care, treatment and recovery of your family member, partner or friend</p> <p>23. You had opportunities to communicate confidentially with the treating doctor if you needed (such as by phone, email or in person)</p> <p>Showing respect</p> <p>24. Your opinion as a carer was respected</p> <p>25. You were identified as a carer of your family member, partner or friend</p> <p>26. Staff conveyed hope for the recovery of your family member, partner or friend</p> <p>Open ended questions</p> <p>27. My experience with this service would have been better if...</p> <p>28. The best things about this service were...</p>		
2	Enabling Practices Scale (24 items) [35]	<p>Comfort with relationship</p> <p>1. The staff and I agree on what is most important in my son's/daughter's program</p> <p>2. It is easy to follow the advice of the staff</p> <p>3. It is easy to work together with the staff when planning my son's/daughter's program</p> <p>4. The staff accept our family's values and beliefs</p> <p>5. The staff care about my son/daughter and my family</p> <p>6. The staff's suggestions for working with my son/daughter make me feel comfortable</p> <p>7. I feel comfortable giving the staff advice if they ask me for assistance</p> <p>8. I feel that I am able to carry out the suggestions of the staff</p> <p>9. The suggestions that the staff make are positive</p> <p>10. I am an equal partner in the relationship I have with the staff</p> <p>11. The staff are happy to accept my suggestions</p> <p>12. With the support of the staff, I am able to solve problems quickly</p> <p>13. The staff consider my family and friends when discussing my son's/daughter's program</p> <p>14. Working with the staff has made me feel more capable</p> <p>Collaboration</p> <p>15. The staff encourage me to contact my family and friends when I need advice</p> <p>16. By following the staff's suggestions I have learned how to deal with family concerns</p>	Frequently used in disability services research. Construct validity yet to be established. Reliability (internal consistency) is good [36]	Respondents: Parents with a child with intellectual disability

	Measure	Items	Psychometric properties	Notes
		17. The staff offer help in response to our family's needs 18. The staff's suggestions for working with my son/daughter at home produce quick results 19. The staff anticipate our family's needs and concerns 20. The assistance the staff gives meets our family's needs Parental autonomy 21. I decide the programs for my son/daughter 22. I am the person who makes the most important decisions about my son's/daughter's program 23. I feel I should be given the most credit for the progress my son/daughter makes 24. I am the person most responsible for the important changes in the life of my son/daughter Response scale: Indicate how much the item applies (to respondent) on a five point Likert scale		
3	Early Childhood Services Survey (ECSS) [37]	Family-orientated services (list of services) 1. Information about where to get services for your child 2. Money to help pay bills 3. Child care 4. Parent or family training 5. Information about specific disabilities 6. Support groups 7. Information about where to get services for your family 8. Information about legal rights 9. Counselling 10. Respite care 11. Sibling support 12. Homemaker and/or housekeeping services 13. Transportation Response scale: Need for service Yes/No Response scale: Service adequacy (if needed) None at all, some but not enough, enough	N/A	Respondents: Parents of children in early childhood service programs Scale scoring: Service adequacy = ratio of total services received to the total number of services indicated as needed/received.
4	Beach Center Family-Professional Partnership Scale [38]	Family-focused questions <i>Your family's service provider:</i> 1. Are available when you need them 2. Are honest, even when they have bad news 3. Use words that you understand 4. Protect your family's privacy	Established factor structure, good reliability (internal consistency) [37-39]	Respondents: parents of children with disabilities

	Measure	Items	Psychometric properties	Notes
		<p>5. Show respect for your family's values and beliefs 6. Listen without judging your child or family 7. Are people that I can depend on and trust 8. Pay attention to what you have to say 9. Are friendly.</p> <p>Child-focused questions <i>Your family's service provider:</i> 10. Help you gain skills or information to get what your child needs 11. Have the skills to help your child succeed 12. Provide services that meet the individual needs of your child 13. Speak up for your child's best interests when working with other service providers 14. Let you know about the good things your child does 15. Treat your child with dignity 16. Build on your child's strengths. 17. Value your opinion about your child's needs 18. Keep your child safe when your child is in their care</p> <p>Response scale: Importance and satisfaction of each item for partnership with a professional serving their child 5-point likert scales 1 (a little important), 3 (important) to 5 (critically important) 1 (very dissatisfied), 3 (neither satisfied nor dissatisfied) to 5 (very satisfied)</p>		
5	Mental Health Statistics Improvement Program (MHSIP) Youth Services Survey for Families (YSS-F) [40]	<p>General satisfaction 1. Overall, I am satisfied with the services my child received. 2. The people helping my child stuck with us not matter what. 3. I felt my child had someone to talk to when he/she was troubled. 4. The services my child and/or family received were right for us. 5. My family got the help we wanted for my child. 6. My family got as much help as we needed for my child.</p> <p>Participation in treatment planning 7. I helped to choose my child's services. 8. I helped to choose my child's treatment goals. 9. I participated in my child's treatment.</p> <p>Access 10. The location of services was convenient for us (parking, public transportation, distance, etc.). 11. Services were available at times that were convenient for us.</p>	Good structure, reliability and convergent validity [40, 41]	Respondents: Parents of children receiving mental health services

	Measure	Items	Psychometric properties	Notes
		<p>Cultural sensitivity</p> <p>12. Staff treated me with respect. 13. Staff respected my family’s religious/spiritual beliefs. 14. Staff spoke with me in a way that I understood. 15. Staff were sensitive to my cultural/ethnic background (race, religion, language, etc.).</p> <p>Social connectedness</p> <p><i>As a result of the services my child and/or family received:</i></p> <p>16. I know people who will listen and understand me when I need to talk. 17. I have people that I am comfortable talking with about my child’s problems. 18. In a crisis, I would have the support I need from family or friends. 19. I have people with whom I can do enjoyable things.</p> <p>Outcomes and functioning</p> <p>20. My child is better at handling daily life. 21. My child gets along better with family members. 22. My child gets along better with friends and other people. 23. My child is doing better in school and/or work. 24. My child is better able to cope when things go wrong. 25. I am satisfied with our family life right now. 26. My child is better able to do things he or she wants to do.</p> <p>Response scale:</p> <p>6-point likert scale 1 (strongly agree), 3 (I am neutral) to 5 (strongly disagree), 6 (not applicable)</p> <p>Open-ended questions</p> <p>1. What have been some of the most helpful things about the services you and your child received over the last 6 months? 2. What would improve the services that you and your child receive from the agency your child receives mental health services?</p>		
6	Child and adolescent versions of the Verona Service Satisfaction Scale (CAMHSSS) [42]	<p><i>What is your view of:</i></p> <p>Overall satisfaction</p> <p>1. The kinds of service offered to your child? 2. The service your child has received, in a general sense?</p> <p>Access</p> <p>3. The appearance and comfort level of the rooms used? 4. How much it cost the family to use the service, including travelling cost, time off work? 5. The length of time before the first appointment?</p>	Good internal consistency, test-retest reliability and sensitivity [42]	Respondents: parents of children receiving mental health services

	Measure	Items	Psychometric properties	Notes
		<p>Effect of services</p> <p>6. The effect of services the effect of services in helping you deal with your child's problems?</p> <p>7. The effect of services in helping you to prevent the return of your child's problems?</p> <p>8. The effect of services in helping your child to feel better?</p> <p>9. How effective the service was in helping you improve your knowledge and understanding of your child's problems?</p> <p>10. How effective the service was in helping the relationship between your child and your family?</p> <p>11. How effective the service was in helping your child to establish good relationships with people outside your family?</p> <p>12. How effective the service was in helping your child do better at school or college?</p> <p>Information</p> <p>13. The explanation of what was going to happen in your child's treatment and why?</p> <p>14. The publicity of information about the available child and adolescent mental health services?</p> <p>15. How information was given to you about the nature of your child's problems and what to expect in the future?</p> <p>Professionals' skills & behaviour</p> <p>16. How the professionals (doctors, psychologists, nurses, therapists) listened to and understood your child's problems?</p> <p>17. The personal manner of professionals?</p> <p>18. The professionals keeping time of appointments?</p> <p>19. The confidentiality and respect for your child's rights?</p> <p>20. Being referred to other services if needed, (for example, to a paediatrician, educational psychologist, or social services)?</p> <p>21. How well different services worked together to help your child (if your child was seen by more than one person or agency)?</p> <p>22. The advice your child was given about what to do between appointments?</p> <p>23. The continuity of care your child has received (that is, seeing the same professionals)?</p> <p>24. The length of time between follow-up appointments?</p> <p>Relatives' involvement</p> <p>25. The advice given to your family or carers about how they could help your child?</p> <p>26. How effective the service was in helping your family or carers to understand your child's problems?</p> <p>27. The ability of professionals to listen to and understand the worries your family or carers may have about your child?</p> <p>28. How information was given to your family or carers about your child's problem and what to expect?</p>		

	Measure	Items	Psychometric properties	Notes
		<p>29. How effective the service was in helping your family or carers deal better with your child's problem?</p> <p>Response scale 5-point likert scale 1 (terrible) to 5 (excellent).</p> <p>Type of intervention</p> <ol style="list-style-type: none"> 1. The response of services to crises or urgent needs during working hours? 2. The arrangements made for after-hours emergencies? 3. Was medication prescribed or recommended for you by a Child and Adolescent Psychiatrist? 4. Did your child receive help to cope with social and school life? 5. Did your child have the opportunity to meet alone, on a regular basis, with a therapist? 6. Was your child admitted (stayed overnight or attended daily) to a Child and Adolescent Mental Health Unit? 7. Did your family or carers have meetings with your child's family therapist? 8. Did your child receive group therapy? 9. Did your family (or carers) have the opportunity to meet on a regular basis with other parents (parents group) of children with similar problems, in order to help to understand and help your child? 10. Did you receive help from the Child and Adolescent Service with your child's education, for example in finding a suitable school or additional support in school? <p>Response scale: Did your child receive this intervention? (Yes/No) <i>If Yes, what is your view of this intervention:</i> 5-point likert scale 1 (terrible) to 5 (excellent). <i>If no, in your view would this intervention have been helpful:</i> Helpful, not helpful, not sure</p> <p>Open ended questions:</p> <ol style="list-style-type: none"> 1. The things I liked most about my experience of the child and adolescent mental health services 2. The things I disliked most about my experience of the child and adolescent mental health services 3. The things I would like to change 		

	Measure	Items	Psychometric properties	Notes
7	Experience of Service Questionnaire (ESQ) (Parent/Carer) [43]	<ol style="list-style-type: none"> 1. I feel that the people who have seen my child listened to me 2. It was easy to talk to the people who have seen my child 3. I was treated well by the people who have seen my child 4. My views and worries were taken seriously 5. I feel the people here know how to help with the problem I came for 6. I have been given enough explanation about the help available here 7. I feel that the people who have seen my child are working together to help with the problem(s) 8. The facilities here are comfortable (e.g. waiting area) 9. The appointments are usually at a convenient time (e.g. don't interfere with work, school) 10. It is quite easy to get to the place where the appointments are 11. If a friend needed similar help, I would recommend that he or she come here 11. Overall, the help I have received here is good <p>Response scale Certainly true, partly true, not true (don't know) ('don't know' response option is not scored)</p>	Evidence for sensitivity and construct validity [44]	<p>Respondents: Parents of children accessing child/adolescent health services</p> <p>Widely used in child/adolescent mental health services, particularly in the UK</p>
8	Family Outcomes Survey - Revised [45]	<p>Knowing rights</p> <ol style="list-style-type: none"> 1. We use available services 2. We know our rights 3. We know who to contact with questions 4. We know options after leaving program 5. We are comfortable talking to provider 6. We are comfortable asking for services 7. We are comfortable making decisions 8. We feel like team members <p>Response scale 4-point likert scale 1 (Not at all), 2 (a little), 3 (somewhat), 4 (almost completely)</p>	Good construct validity and reliability (internal consistency) [46-48]	<p>Parents of children accessing services for disabilities or developmental delays</p> <p>5 subscales in full survey. 'Knowing rights' subscale items reported here (most relevant)</p> <p>Other domains Understanding strengths; helping child develop & learn; having support systems; accessing the community</p>

	Measure	Items	Psychometric properties	Notes
9	Youth and caregiver Service Satisfaction Scale (SSS) [49]	<ol style="list-style-type: none"> 1. Did this youth get the kind of services you think you needed? 2. If another youth were in need of similar help, would you recommend our services to him or her? 3. If this youth were to seek help again, would you seek it from us? 4. Were the services you received the right approach for helping this youth ? <p>Response scale 1 (No, definitely not') to 4 (Yes, definitely').</p>	Reliability (internal consistency), model fit [49]	<p>Respondents: Caregivers of youth receiving mental health services</p> <p>Adapted from the CSQ-8 (Brannan et al, 1996)</p>
10	Measures of Processes of Care (MPOC) (20 items)[50]	<p>Evaluation of the quality of family-centred service provision:</p> <ul style="list-style-type: none"> • Enabling and partnership (3 items) • Providing general information (5 items) • Providing specific information about the child (3 items) • Coordinated and comprehensive care for child and family (4 items) • Respectful and supportive care (5 items) 	Established reliability, validity & sensitivity [50-52]	<p>Respondents: Parents of children receiving health services</p> <p>Extensively used in Canada.</p> <p>Copyright owned by CanChild researchers. Permission and licensing agreement required for use and can be purchased from https://canchild.ca/show</p>
11	European Parent Satisfaction Scale about Early Intervention[53]	<p>Assistance/care for parents</p> <ol style="list-style-type: none"> 1. I think that the assistance, care, and support offered to me by the service in general is: 2. The assistance and care provided by the service has helped me to change the view I have of my child: 3. The assistance and care provided by the service helped me to handle my emotions: 4. With the information about existing services and interventions, I can better see which services my child needs: 5. The assistance and care provided by the service helped me to see my child's possibilities and difficulties: 6. The assistance and care provided by the service helped me to feel more secure in dealing with and handling my child: 7. I have more fun with my child as a result of assistance and care provided by the service: 	Evidence for internal consistency and content validity [54, 55]	<p>Respondents: Parents of children receiving early intervention services</p> <p>Items reported from Ziviani et al (modification of phrasing for Australian context) [55]</p> <p>Seven subscales in full survey (more relevant reported here): 1. Assistance/care for parents</p>

	Measure	Items	Psychometric properties	Notes
		<p>8. I was provided with new ideas for the daily care and education of my child through the assistance I received:</p> <p>9. I think that there are enough opportunities to get in contact with other parents if I want to:</p> <p>10. The contact I have with other parents is helping me:</p> <p>11. The early intervention (EI) service informs me about financial assistance that is available to me:</p> <p>12. The EI service informs me about administrative issues:</p> <p>13. The EI service informs me about different community services available for my child:</p> <p>14. I think that the information provided by the EI service about my child's disabilities/special needs has been helpful:</p> <p>15. I think that the service has provided opportunity for group activities for parents:</p> <p>Relationship Between parents and service providers/professionals</p> <p>16. I have the feeling that the service providers from the EI program understand me:</p> <p>17. I have the feeling that the service providers from the EI program protect our confidentiality:</p> <p>18. I may speak to the service providers from the EI program about my doubts and concerns in regard to the assistance and care my child receives:</p> <p>19. The service providers from the EI program accept my decisions:</p> <p>20. I have an active part in making decisions:</p> <p>21. The service providers from the EI program answer my questions:</p> <p>Services of other community agencies</p> <p>22. I think that the service providers are aware of other community agencies to which we could</p> <p>23. be referred:</p> <p>24. The accessibility of other community agencies is:</p> <p>25. The flexibility of other community agencies is:</p> <p>Additional comments [open-ended responses]</p> <p>Response scale Neutral statements rated using bad/good scale anchors (e.g., Q1), positively worded statements rated using disagree/agree scale anchors (e.g., Q2) -2 (very bad/I strongly disagree) 0 (neither good nor bad) to +2 (very good/I strongly agree), not relevant/not applicable</p>		<p>2. Assistance/care for children</p> <p>3. Social environment</p> <p>4. Relationship between parents and service providers/ professionals</p> <p>5. Model of assistance/ care</p> <p>6. Parents' rights</p> <p>7. Services of other community agencies</p>

Note. Item number may differ from order of items in original instrument (items sorted by domain measured for ease of review).

Table 2 Examples of measures of secondary stigma

Note. Item number may differ from order of items in original instrument (items sorted by domain measured for ease of review).

	Measure	Items	Psychometric properties	Notes
1	Internalized Stigma for Substance Abuse Scale for Caregivers (ISSA-C) [33]	Unidimensional (no subscales) <ol style="list-style-type: none"> 1. I feel out of place in the world because my loved one has a substance use problem 2. Substance using people tend to be violent 3. People discriminate against me because my loved one has a SU problem 4. I avoid getting close to people who don't have SU problems to avoid rejection. 5. I am embarrassed or ashamed that my loved one has a SU problem 6. People with SU problems shouldn't get married 7. People with SU problems make important contributions to society 8. I feel inferior to others who do not have a loved one with a SU problem 9. I don't socialize as much as I used to because my loved one's SU problem makes me look or act weird 10. People with SU problems can't live a good or rewarding life 11. I don't talk about myself or my family much because I don't want to burden others with my loved one's SU problem 12. Negative stereotypes about SD keep me isolated from the "normal" world 13. Being around people without SU problems makes me feel out of place or inadequate 14. I feel comfortable being seen in public with a person who has an obvious SUD 15. People often patronize me or treat me like a child because my loved one has a SUD 16. I am disappointed in my loved one for having a SU problem 17. Having a SUD has spoiled my loved one's life 18. People can tell my loved one has a SUD by the way they look 19. Because my loved one has a SUD, I need to make decisions for them 20. I stay away from social situations in order to protect my family and friends from embarrassment 21. People without a loved one with a SUD couldn't possibly understand me 22. People ignore my loved one or take them less seriously because they have a substance abuse problem 23. My loved one can't contribute to society because they have a substance abuse problem 24. Living with a SUD loved one has made me a tough survivor 25. Nobody would be interested in getting close to me because my loved one has a SUD 26. In general, I am able to live my life the way I want to 27. My loved one can have a good fulfilling life despite their SUD 28. Others think my loved one can't achieve much in life because of their SUD 29. Stereotypes about people with SUDs apply to my loved one 	Preliminary results indicate good construct validity and internal consistency [33]	Respondents: Caregivers or supporters of people who use drugs/alcohol Instrument: Contact researchers for copy and use Scale Scoring: Items 14, 24, 26 and 27 are reverse coded prior to scoring. Higher scores indicate higher levels of internalized stigma for caregivers

	Measure	Items	Psychometric properties	Notes
		<p>Response scale 4-point likert scale 1 (strongly disagree), 2 (disagree), 3 (agree), 4 (strongly agree)</p>		
2	Parents' Self Stigma Scale (PSSS) [56]	<p>Three subscales: self blame, self shame, bad parent self-beliefs</p> <ol style="list-style-type: none"> 1. My child has his/her problem because of me 2. The way I have raised my child has contributed to his/her problem 3. I deserve to be blamed for my child's problem 4. I feel guilty that my child has his/her problem 5. It is not my fault that my child has his/her problem 6. I am embarrassed that my child has his/her problem 7. I am ashamed that my child has his/her problem 8. I am self-conscious about being a parent of a child with problems 9. I am the best parent I can be 10. I am a good parent, no matter what others say 11. I am not a good enough parent <p>Response scale 5-point likert scale 1 (never) to 5 (almost all the time)</p>	Strong content validity, convergent validity and acceptable internal consistency [33, 56, 57]	<p>Respondents: Parents of children with mental health or related disorders</p> <p>Instrument: Contact researchers for copy and use</p> <p>Scale Scoring: Score for each item is summed for a total score. Higher scores indicate higher levels of parenting self-stigma.</p>
8	Self Stigma of Seeking Help (SSOSH) [58]	<p>Unidimensional (no subscales)</p> <ol style="list-style-type: none"> 1. I would feel inadequate if I went to a therapist for psychological help 2. My self-confidence would NOT be threatened if I sought professional help 3. Seeking psychological help would make me feel less intelligent 4. My self-esteem would increase if I talked to a therapist 5. My view of myself would not change just because I made the choice to see a therapist 6. It would make me feel inferior to ask a therapist for help 7. I would feel okay about myself if I made the choice to seek professional help 8. If I went to a therapist, I would be less satisfied with myself 9. My self-confidence would remain the same if I sought help for a problem I could not solve 10. I would feel worse about myself if I could not solve my own problems <p>Response scale 5-point likert scale 1 (strongly disagree), 2 (disagree), 3 (neither disagree nor agree), 4 (agree), 5 (strongly agree)</p>	High internal consistency and good test-retest reliability. Good construct and criterion validity. Good cross-cultural validity [58]	<p>Respondents: Anyone</p> <p>Instrument: Contact researchers for copy and use</p> <p>Scale Scoring: Items 2,4,5,7 and 9 are reverse coded prior to scoring. Higher scores indicate higher levels of stigma about seeking help</p>

Note. Item number may differ from order of items in original instrument (items sorted by domain measured for ease of review).

7. References

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Appendix A: Outcomes frameworks addressing family outcomes

Note. These Outcomes Frameworks address services for children and youth. Listed here as examples of Outcomes Frameworks focused on families outcomes.

Australia

Families first outcomes evaluation framework (UNSW)

https://cphce.unsw.edu.au/sites/default/files/uploads/Families_First_Evaluation_Framework.pdf

Building a better outcomes framework for families: A story from the Mallee (Social Ventures Australia)

<https://aifs.gov.au/cfca/webinars/building-better-outcomes-framework-families-story-mallee>

International

Oranga Tamariki Outcomes Framework (NZ)

<https://www.orangatamariki.govt.nz/about-us/how-we-work/outcomes-framework/>

Herefordshire's Family Outcomes Framework (UK)

https://www.herefordshire.gov.uk/downloads/file/3747/herefordshires_family_outcomes_framework.pdf

County Durham Family Outcome Framework. Children and Young People's Services Children's Services. (UK)

<https://durham-scp.org.uk/wp-content/uploads/2020/03/Family-Outcome-Framework-Reviewed-MARCH-2020-DSCP-002.pdf>