



Carer Engagement Report

Prepared for:

**Mental Health Commission
Young People Priority Framework**

October 2020

Foreword

Carers of young people who have mental health or alcohol and other drug challenges are fundamental to the recovery journey of those for whom they care. The emotional investment that carers have is sometimes palpable, and frustration often underscores their daily experience.

'Carers are broken and exhausted...we need to be taken on the journey.'

The quote included above, is from a carer who attended one of the consultation forums. It expressed the sentiment of most carers who engaged with YACWA to have their voices heard for the development of the Mental Health Commission's Young People's Priority Framework (YPPF).

Carers came to this consultation with many solutions and with enthusiasm and energy for change. They expressed appreciation for the opportunity to have their voices heard. What is clear, is that carers have the expertise that only lived experience can bring and can add significant value to the future design of a more accessible, coordinated and well-functioning service system for the young people for whom they care.

This project would not have been possible without the input and promotion of the many agencies in Western Australia who support carers. I would like to extend my gratitude on behalf of YACWA to these organisations for their effort and collaboration through this rapid process and in appreciation of the great work they all do each and every day, supporting carers and their families.

YACWA also thanks the Mental Health Commission for ensuring that the voices of carers are heard in the design of the YPPF and going forward in its implementation.

We hope that the key messages shared by carers are heard loud and clear by policy makers and that this project leads to positive change for young people and those who love and care for them.



Ross Wortham

CEO, Youth Affairs Council of WA

YACWA acknowledges Aboriginal and Torres Strait Islander People as the traditional owners and custodians of this land and its waters. We wish to pay our respects to Elders past, present and extend this to all Aboriginal People seeing this message.



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Executive Summary

In September 2020, YACWA was contracted by the Mental Health Commission (MHC) to undertake an engagement with family carers of young people who have mental health and/or drug and alcohol concerns. This engagement was to inform the development of a State-wide Young People Priority Framework (YPPF). The aims of the YPPF will be to guide the current and future mental health and AOD sector in supporting and responding to the needs of young people aged 12 to 24 years.

The intent of the engagement has been to:

- Determine gaps, challenges across the mental health and AOD service system (from prevention and early intervention through to treatment and acute care) for young people aged 12 to 24 years.
- Provide input into an agreed vision for WA, regarding the mental health and AOD service system for young people aged 12 to 24 years.
- Determine opportunities for improvements, next steps for the system and key areas of focus for the State and the strategies required to achieve the agreed vision.
- Consider whether evidence supports aligning the mental health and AOD age cohorts; and if so, provide recommendations for how this could be achieved.

Over the duration of the consultation, YACWA engaged with 85 family carers through a survey, group forums and one to one interviews. The vast majority of these were women which matches with ABS data that women are by far the majority of primary carers for young people with mental health and AOD issues. The majority of carers we spoke with lived in the Perth metropolitan area, with the only regional input coming from the survey data.

The carers' voice has been heard loudly in this consultation process. There are clearly high levels of dissatisfaction with the current service system among carers of young people who are using mental health and AOD services.

While the frustration and sadness among carers is palpable, the overwhelming sentiments among carers who were part of this consultation was love and care for their children, grandchildren and loved ones who have been impacted by their experiences.

Encouragingly, carers came to this consultation with many solutions and with enthusiasm and energy for change. They expressed appreciation for the opportunity to have their voices heard and were keen to be part of any service system co-design. What is clear from this consultation is that carers have the expertise that only lived experience can bring and can add significant value to the future design of a more accessible, coordinated and well-functioning service system for the young people for whom they care.

The results of this consultation show significant alignment with the outcomes of the recent consultation with young people on the future vision for the service sector and the development of the Young People Priority Framework. It is pleasing that carers and young people share some aspects of the future vision.

The data from all of the engagement methods was collated and analysed for themes. Five clear key priority issues emerged:

- Accessibility
- Service coordination and consistency
- Carers wanted services to be more flexible
- Better integration of AOD and mental health services

- Early identification and intervention
- Whole person assessment and care
- Carer support and collaboration

Accessibility. Carers told us that there was a real gap in service provision for 16 to 18-year old age group, especially with inpatient services. Carers spoke of the frustration of being caught in a situation where the care needs of the young person fell back on them as the service system did not have any solutions to support the young people in this age group. Carers from regional and outer-suburban areas spoke about the need for more accessible services and all carers spoke about the need for more services to ensure that waitlists are reduced. They told us the more funding to reduce the overall cost of services would be welcomed, particularly as complex and multi-dimensional issues take some time to treat and resolve.

Service coordination and consistency. Carers almost universally spoke about the need for services to coordinate and collaborate better for there to be consistency across services. They felt that this could be achieved by better centralised referral, information, and coordination systems. They wanted for services to be better connected and for there to be 'no wrong door' and ongoing touchpoints for carers and young people.

Carers wanted services to be more flexible. There was strong interest in expansion of outreach services, in particular to support young people and families post inpatient admission. Carers said that services were variable depending on postcode, and that this could be improved by having service hubs in key areas supported by assertive outreach programs.

Better integration of AOD and mental health services was strongly supported by carers. Ensuring that there are multi-service agencies which can address both types of issues was seen as a critical missing component in the current service system. In addition, some carers spoke about the integration of mental health and disability support, particularly in the treatment of autism, ADHD, and other co-existing diagnoses.

Early identification and intervention. Many carers spoke about their wish for improved information and education across society and within the service system to reduce stigma and improve the early identification and intervention for mental health and AOD issues. They thought that this could include better embedding education on these issues within the school curriculum and also more broad-based awareness raising across the community.

In addition, carers highlighted the need for GPs and hospital frontline health staff to be better trained and prepared for youth mental health and AOD presentations.

Whole person assessment and care. Holistic services which ensure a bio-psycho-social approach to assessment and treatment were part of the carers' vision for the service system. Rather than each discrete part of the system dealing with a small part of the young person's issues, carers said that the service should be able to 'wrap around' the young person and their family to provide a more holistic service. They said that this would prevent the need for young people to transition so often and to have to be on multiple wait lists and repeat their story to different clinicians and support staff. They said that this holistic approach should include a strong focus on peer and consumer-led service delivery—something that was very much valued by carers.

Carer support and collaboration. Carer's said that carer support services were strongly valued and suggested increasing funding for these services, including improving respite availability and other support structures. In addition, carers suggested better consultation and governance mechanisms that include the carers' voice be implemented, including ensuring that carer and family inclusion are legislated and involved in service co-design and review.

Project background

The Youth Affairs Council of Western Australia (YACWA) is the peak non-government youth organisation in Western Australia. We operate primarily as a human rights organisation that seeks to address the exclusion of young people in a rapidly changing society.

Estimates of the number of carers in Australia vary. Some estimate that up to 15% of the Australian population care for someone with a mental illness (Pirkis et al. 2010). ABS figures from 2015 suggest around 93,000, while further analysis of these figures suggest the actual numbers are more like 240,000 (Diminic et al. 2017; Carers Australia 2019). These figures are likely to be underestimates as many people do not identify themselves as carers and see caring as part of their role as parent or partner (Quinlan et al. 2018). This is especially true for people from Aboriginal, Torres Strait Islander and CaLD backgrounds (Diminic et al. 2017; Poon & Lee 2019). Young carers are also likely to be severely underrepresented in these figures and are at particular risk of disadvantage (Carers Australia 2019). Better and more consistent data collection would enable better service delivery for carers (Dept of Communities ND).

One of the difficulties with estimating the numbers of mental health carers is the way caring is defined in the ABS data. The focus is on practical care for people with physical disabilities. Mental health carers spend most of their time providing emotional support and reassurance to their loved ones (Diminic et al. 2017; Quinlan et al 2018; Carers Australia 2019).

The figures indicate that most mental health carers are women and most of them are caring for their partner or son or daughter (Pirkis et al. 2010, Diminic et al. 2017). Carers generally have lower incomes, lower workforce participation rates and lower education levels than non-carers (AIHW 2017). Mental health and AOD carers come from across our community and anyone could be thrust into this role.

Mental health and AOD family carers experience a range of difficulties. These include physical and emotional overload, depression, anger, shame, guilt, frustration, and family conflict. They suffer financial difficulties as paid work is difficult to maintain, because of the episodic nature of many illnesses. This also makes planning respite for themselves exceedingly difficult. Some illnesses require intensive support including medication management, as well as monitoring self-harm and suicidality; and carers sometime face risks to their own safety. They struggle with balancing their own needs and those of their unwell family member. Carers struggle with their own mental health, social isolation, poor quality of life, and complicated grief (Broady & Stone 2015; Quinlan et al 2018; Poon & Lee 2019).

Family carers often have difficult relationships with staff in mental health services. Explanations around mental illness being caused by disordered family structure, though now less popular, are still widespread among clinical staff, which leads to stigma against families. Carers also struggle with privacy issues in services; they are expected to do most of the care of their loved ones, and yet often have no access to critical information about them (Bland & Foster 2012; Fox et al. 2015).

Stigma is also widespread in the community especially around severe illnesses. This stigma is often transferred to carers and this courtesy stigma contributes to their social isolation (Fox 2015). At a systemic level, de-institutionalization, the introduction of the NDIS and changes to funding of carer services are further challenges inhibiting support for carers and the young people they care for.

Consultation process

The engagement phase for this project ran from the 29th September to the 16th October 2020. In total 85 family carers were involved in the consultations across all different engagement types. YACWA promoted the engagement activities in the following ways:

- Emails to a key sector contact list including Carers WA, Helping Minds and MIFWA and including targeted correspondence to carer service contacts considered particularly relevant
- Follow up phone calls to key agency contacts
- Social media promotion on YACWA and Carers WA's Facebook and Instagram platforms
- Inclusion of information in YACWA, Carers WA and MIFWA's e-news

There were three methods of engagement employed during the consultation phase:

1. [An online survey](#)
2. [Face to face group forums](#)
3. [One to one consultations](#)

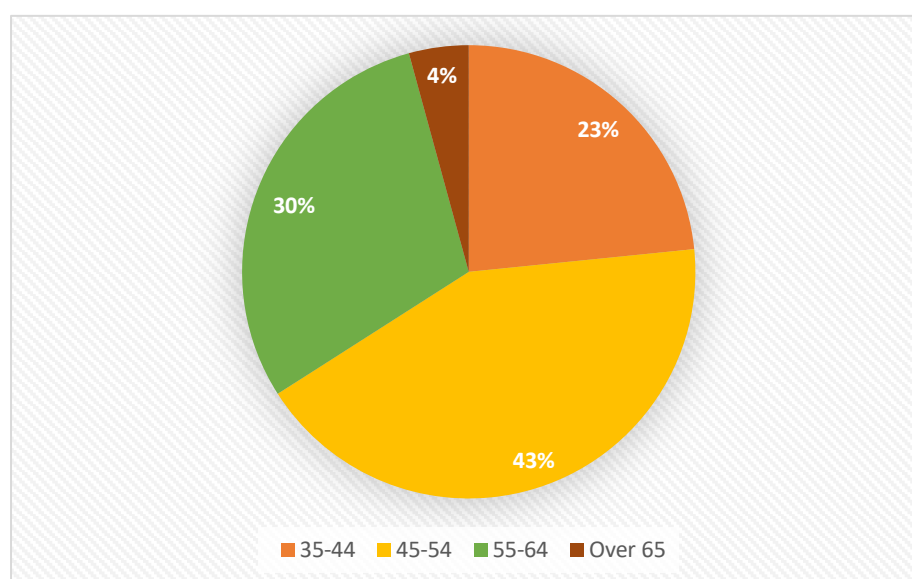
Online survey

An online survey was used to reach a broad group of family carers, and to allow some who would not be comfortable or available to discuss their views in person to have their say. The survey was based on the youth survey, with additional questions around supports for family carers included. The survey was open from 1st October to 12th October 2020. The survey questions are included in [Appendix A](#).

In total, 48 family carers completed the survey. Demographic detail on these participants is provided below.

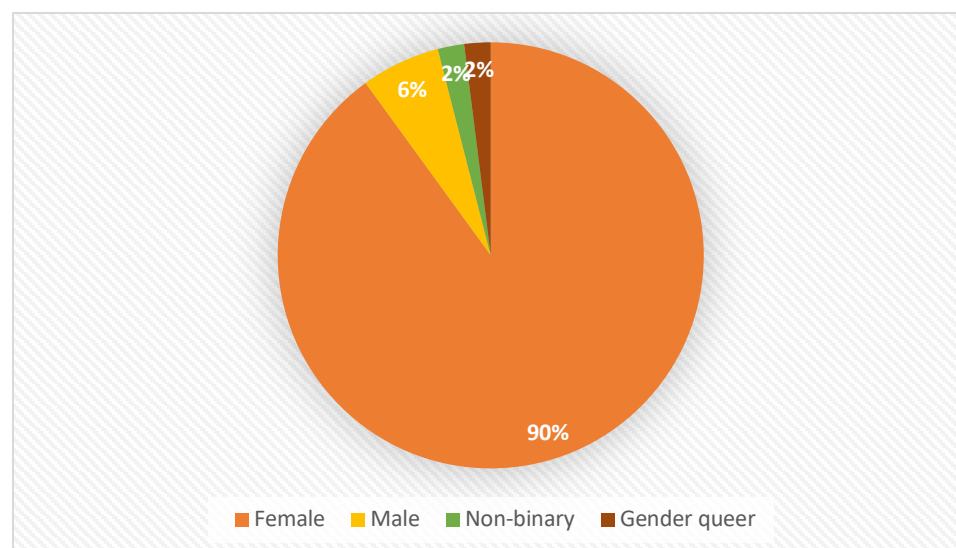
The largest group of respondents (43%) were in the 45 to 54 age range. Significant numbers were also seen in the 55 to 64 (30%) and 35 to 44 (23%) age ranges. Smaller numbers in the over 65 age range (4%) responded.

Figure 1: Age of survey respondents



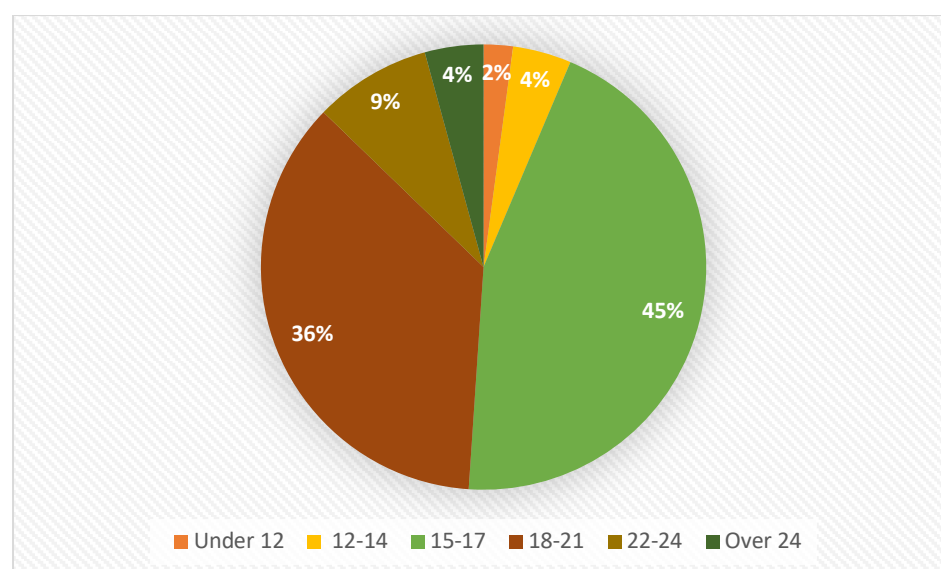
Females comprised 90% of survey respondents, with only 6% identifying as male, 2% as non-binary and 2% as gender queer. This matches with the ABS data which reports that women are by far the majority of primary carers for young people with mental health and AOD issues.

Figure 2 Gender identity of survey respondents



In terms of the age of young people who they were caring for, 45% of carers were caring for young people aged 15 to 17. The next highest percentage was the age group 18 to 21 with 36% caring for this age group.

Figure 3: Age of young people the survey respondents were caring for



In terms of how long the survey respondents had been providing care, 52% had been providing care to a young person for 11 years or longer, 11% for five to ten years and 37% for one to four years.

Other demographic data of survey respondents included:

- 10% were from a refugee or migrant background

- 4% identified as being Aboriginal or Torres Strait Islander
- 20% identified that they were living with a disability
- 9% of survey respondents identified as either lesbian, gay, bisexual, transgender, intersex, queer/ questioning or asexual/agender

In terms of where they lived, 92% of respondents lived in the Perth metropolitan area, in diverse suburbs north and south of the river. One respondent was from the Bindjareb (Pinjarra) region and three respondents were from the South West region.

Face to face group forums

Three in person forums took place on the 14th October in Rockingham, the 15th October in Leederville and the 16th of October in Midland. There was a forum planned for Joondalup, however this was cancelled due to low numbers and the three people who had registered were instead engaged in one on one interviews. In total, 28 family carers attended these forums. Demographic information for these participants was not collected.

These forums were facilitated by the lead consultant. Family carers were asked specific questions (see [Appendix B](#)) and their responses recorded by staff at the event. There were large numbers booked into the Leederville forum, so family carers were divided into small groups with these groups feeding back responses to the whole group. Two YACWA team members were at each session and took notes. Family carers also wrote their own responses in their small groups.

One to one consultations

One to one telephone or zoom consultations were offered to family carers who were unable to attend the group forums. They were also offered to family carers who expressed an interest in the online forums. Online forums were not held because the level of interest was low. Nine one to one consultations were conducted. Eight of these carers were female, one was male, and all lived in the Perth metropolitan area.

Participants were engaged for approximately one hour in one to one interviews and the questions asked were similar to those used for the group forums (see [Appendix C](#)).

Consultation outcomes

This section provides an overview of the data collected through all methods of consultation. This has been broken down into the survey data and then the data collected through the forums and one on one interviews. The reason for the separation is to allow for separate analysis as the data collection method was quite different.

Survey data

The online survey was designed to ask about carer's experiences with mental health and AOD services and family carer supports as well as their opinions about service improvement. In addition, to align with the lines of inquiry for this consultation, family carers were asked about their vision for the mental health and AOD service systems.

The following sections report on the responses to the survey based on the questions asked, separating them into categories in line with the survey structure.

Use of services

Youth mental health and AOD services

Of the 48 carers who responded to the survey, 92% cared for young people who had used a mental health service and 15% cared for young people that had used an AOD service. Mental health services used covered a wide range from private and community-based counselling services, helplines, CAMHS and inpatient hospital settings. AOD services used included DAYS, Cyrenian House and the North Metro Drug Service.

Respondents were asked to report if they had not used mental health or AOD services and to indicate a reason why. There were only six responses to this question, with the main responses being that they had not been able to access services due to restrictions including age, wait list, cost and also that the young person had refused to access a service. It is important to note that those who did not access services at one time may have reported accessing services at another time. The two questions in this case are not mutually exclusive.

Carer support services

Carers were asked if they had accessed carer support services. Almost 66% of respondents reported using some carer support service. Those who had not accessed services listed a wide range of reasons, including lack of time, a negative experience with a service, lack of knowledge of support or receiving support from family or other people in their network.

Service quality

We asked carer's about service quality in relation to both mental health and AOD services that the young person they cared for used and that they themselves had used for support.

Youth mental health and AOD services

Carer's were presented with three statements around service quality of youth mental health and AOD services and asked to respond to a scale from strongly agree to strongly disagree for each.

When asked if services had **met their expectations**, 14% responded positively, 19% responded neutrally and 67% responded negatively.

When asked if services **responded well to their family member's mental health and AOD needs**, 14% responded positively, 26% responded neutrally and 60% responded negatively.

Some carers reported limited success with some services and particular clinicians, but generally there were few positive comments on service quality, with many respondents using the free text box under this question to list in detail all the ways they'd been let down by the system.

'I've been disappointed and frustrated that we have been unable to obtain enduring support for my daughters ADHD/mental health/probable autism. CAMHS wouldn't take us and we have just been dropped by our private psychiatrist. My expectation of the public system was very, very low and my expectation was met.'

'I am disgusted with most of the Mental Health system in WA'

'The ed was horribly traumatic and extremely rude'

'CAMHS refused support stating our child didn't need crisis help and lied about what we spoke about in the intake meeting to a referring psychologist who then refused to see him because he wasn't medicated and too unstable for her to work with. Left [public treatment service] very upset and disappointed trying to get help and diagnosis with severe anxiety.'

'There are serious systemic gaps and flaws in services for Eating Disorders in WA.'

'I am disgusted with most of the Mental Health system in WA. If it wasn't for MIFWA, I would have been in hospital with my daughter who has the illness!'

There were some comments with mixed positive and negative feedback:

'Early in our journey with a daughter with anorexia. Feel very lucky to be able to access a private inpatient clinic. Public services have extraordinary waiting times.'

'Disjointed services in the private sector, psychiatrists who seem to be primarily concerned with risk management rather than patient management. Excellent private clinical psychologist who basically saved my young person's life.'

We asked carers if mental health and AOD services responded well to their **cultural needs**. Thirty-two carers responded to this question of which about 25% reported that the service(s) had responded well, 26% were neutral and 14% reported that the service(s) had not responded well. Nearly 36% of respondents recorded N/A for this question.

Carer support services

Carer's were presented with three statements around service quality as it related to carer support services and asked to respond to a scale from strongly agree to strongly disagree for each.

When asked if services had **met their expectations**, 39% responded positively, 19% responded neutrally, 19% responded negatively and 25% selected n/a for this statement.

When asked if services **responded well to support needs**, 44% responded positively, 8% responded neutrally, 22% responded negatively and 25% selected n/a for this statement.

Overall, carers were a lot more positive about the support they had received as carer's than the care the young person that they cared for had received.

'The education we received from PCH ED Program was invaluable and our Care Co-ordinator has been supportive of us throughout.'

'Good support from both Mifwa - groups and Helping Minds - groups and counselling. Carers WA has also been helpful'

'So very thankful to MIFWA, met my needs and exceeded my expectations.'

However, there was also some mixed feedback and areas for improvement.

'There is no finding for help for our family in my child's NDIS plan and there really should be for the person who is directly caring for them. Also, the NDIS plans don't accommodate for childcare if the other child has ADD or is "Normal"'

'There is an issue with Helping Minds intake - every time I ring to book into something, I have to tell the person on the phone my story all over again'

Carers were asked how services resounded to their cultural needs. Almost 17% of respondents agreed that services responded well to their cultural needs, 28% were neutral, 8.5% disagreed and 47% recorded N/A for this part of the question.

We asked carers if mental health and AOD services responded well to their **cultural needs**; 17% responded positively to this, 28% neutrally, 8% responded negatively to this statement and 47% selected n/a.

Service accessibility

To find out about mental health and AOD service provision accessibility and family carer support we asked family carers to respond to series of statements using a scale from strongly agree to strongly disagree. Carers were able to comment on their answers in free text fields at the end of all of the questions. Concerningly the majority of responses held a negative view of the current services accessibility.

Youth mental health and AOD services

We asked family carer's how **confident they were in finding mental health and AOD services** to meet the needs of the young person they cared for. In total, 13 responded to this question, 31% agreed, 8% were neutral and 61% disagreed.

We asked family carers if they thought mental health and AOD services responds well to young people that have a range of **different needs and come from a diversity of backgrounds**. Only six people responded to this statement, but they all disagreed.

We asked family carers if there was **good access to mental health and AOD services in the area they lived**. In total, 14 responded to this statement with 14% responding neutrally and 86% disagreeing.

We asked family carers in a free text field to list three things that they **liked about the current mental health or AOD services system and family carer supports** in WA. Respondents to the survey did have some positive impressions of the current system.

Some of the key quotes and words used were:

- Private works well if you can access it
- When you find a service like Youth Focus, it is invaluable
- The staff are always supportive and sympathetic
- Some of the services and clinicians are very caring and helpful
- Skilled workers, caring staff, staff relate well to young people
- Inclusive services
- They don't judge
- Inpatient stays have been a safety net for us
- Support groups with others in similar circumstances
- Modern facilities

We asked carers to tell us three things that they **didn't like about the current mental health or AOD services system and family carer supports** in WA. Respondents identified a number of challenges with there being four main themes:

- Communication and coordination issues within and between services
- Long waitlists (all services) and expensive private services
- Poor quality of services, not enough services
- Lack of accessibility, particularly in regional areas

'Often issues like AOD or mental health exclude people from other services and there's no service that caters for all these issues.'

Solutions

The final group of questions in the survey centred around what is **missing from the mental health and AOD service system and family carer supports** and how the system could be improved. Carers were asked their perception of what is missing from the system currently.

Some key themes that emerged from this question include:

- Better promotion and awareness raising of services, both for young people and carers
- Better coordination and liaison between services
- More holistic service provision, i.e. AOD, mental health and disability services
- Reducing service gaps between acute and community based entry-level services
- Improving the accessibility of services, particularly in regional areas

'Care. Individual focus. Consistency and continuity of care. Consumer-led recovery. Holistic community care - during prevention, education, crisis, and aftercare.'

Carers had a variety of ideas covering a range of service types and perceived problems in the service system. Many of the ideas are included in the table below.

<i>Children to be taught mindfulness in primary school</i>	<i>Access to community based services before crisis point</i>	<i>Step-down facility for eating disorder patients</i>	<i>Sibling support, education and networking for carers</i>	<i>Working farm for young people where they also receive therapy</i>
<i>GP training in mental health issues, particularly eating disorders</i>	<i>More residential facilities for young people- step down from acute beds</i>	<i>Family meetings and better communication between carers and clinicians</i>	<i>More and better trained mental health staff who are empathic and professional</i>	<i>More scope for who current services can see- integration across AOD and mental health</i>
<i>More funding for carer support agencies</i>	<i>More options for carer respite</i>	<i>Work together and develop plans in an holistic way</i>	<i>More outreach worker options</i>	<i>Client centred approach in all treatments</i>
<i>More peer/ consumer-led programs</i>	<i>Easier, more accessible referral system</i>	<i>More funding to reduce wait lists</i>	<i>More step up/ step down services</i>	<i>Education about mental health and AOD in schools and community</i>

The final question in this section allowed carers to provide ideas for the future improvement of the system. Carers were asked to imagine that they had **control of government decision making in the area of mental health and/or AOD services**. The responses can be broadly categorised into the following thematic areas:

- Better access to services
- Expansion of services
- Better coordination of services, continuity of service and communication between services
- Ensuring greater consumer and carer input into services

The table below details many of the carers' responses to this question.

<i>Mental Health Care Plans longer for low income earners</i>	<i>Better service accessibility in small towns and regional areas</i>	<i>More funding and resources across the service system</i>	<i>Residential facilities with holistic, coordinated care</i>	<i>Caregiver inclusion legislation</i>
<i>Central information and referral point.</i>	<i>Improved communication and coordination between services</i>	<i>Better training and support for staff</i>	<i>Expansion of inpatient facilities</i>	<i>Early access and intervention to services</i>
<i>More respite opportunities for carers and siblings</i>	<i>Carer and consumer led review panel for complaints</i>	<i>Continuity of care, better transitions between services</i>	<i>Allow young people to access services for longer periods of time</i>	<i>Holistic approach</i>
<i>Put decisions in the hands of people with lived experience</i>	<i>Easier admission process for those in distress</i>	<i>More flexibility in service continuity (across age ranges)</i>	<i>More funding, and more inpatient facilities</i>	<i>More systematic and centralised information and referral process</i>

In-depth consultation data

Consultation with family carers using in-depth interview and group forum discusses resulted in high quality qualitative information. Issues were able to be explored deeply and follow up questions were asked to flesh out key themes and ideas. This section summarises data from the following consultation methods:

- Face to face forums
- One to one consultations

Future vision

Family carers were specifically asked to imagine a future service system that would better meet the needs of all young people who needed to access a service. This was designed to align with the line of inquiry for this consultation which was consistent across all sector and carer consultations as well.

The key themes for the future vision of the mental health and AOD systems, according to carers, can be grouped in the following categories:

- Accessibility. They wanted a more flexible, accessible approach to service delivery with better communication between services and gaps in service addressed.
- Service coordination and consistency. Carers highlighted the need for services to work together, collaborate and to integrate to deal with multiple co-existing issues for young people if necessary.
- Early identification and intervention. Carers said there need to be an improved approach to education across society, reducing stigma and ensuring that health practitioners are well prepared to identify mental health and AOD issues in young people.
- Whole person assessment and care. Carers consistently talked about the need for holistic services which treat multiple issues with a focus on peer and consumer-led service delivery.
- Carer support and collaboration. Carers highly valued carer services and spoke about the need to include carers and their support services in co-design and review of services.

The final words are from a carer, who expressed their wish for the future of the mental health and AOD service system for young people:

'One system for it all. Change it so there's no silo-ing that excludes people from getting help and exhausting people when they get bounced from one sector to the other. Sectors need to work together so it's not this hard to get help.'

What's working well

Family carers were asked to tell us what they thought was working well in the mental health and AOD service systems.

Family carers reported having good experiences with the Mental Health Advocacy Service. Most family carers of young people with eating disorders spoke positively about the PCH Eating Disorder Program, and many liked the treatment their young person received in the Youth Mental Health Unit at Fiona Stanley Hospital.

Carers appreciated peer support from people who have been on the same journey as themselves. They reported particularly liking the services provided by Helping Minds and MIFWA. Family carers of young people with eating disorders liked the EDFA Strive support group.

'Most helpful is just being with other parents of kids suffering mental health issues'

A summary of responses as they relate to services for young people and services for carers that family carers believe are working well is outlined below.

Services for young people

- Mental Health Advocacy Service is fantastic
- Medicare rebates are helpful
- The Medicare mental health plan for 40 sessions for eating disorder patients is good
- Mental health admissions worked well as respite for both carer and young person
- Family education program at PCH Eating Disorder Program
- Care coordinator at PCH Eating Disorder Program is a good model of care that should be extended to other services
- Fiona Stanley Youth Mental Health ward for eating disorder patients - some really good staff, some not so good
- A GP who had an awareness around mental health, he knew to refer to a psychiatrist for medication. The GP knew the psychiatrist he was referred to.
- ICOT Joondalup – is good service
- Booked admissions
- Crisis admissions
- Crisis phone line
- Emergency Department - one carer had mostly good experiences
- Good care in Fiona Stanley
- Telehealth services - needs to be kept on
- ECT for very unwell young people
- Support workers through NDIS for unwell children so carers have time off.
- Fiona Stanley Hospital - Fast track to ward, avoid ED for young person known to staff
- Some good clinicians

Services for carers

- Helping Minds carer counselling and carer advocates
- Helping Minds counsellor who also knew about respite services
- MIFWA – you can call them to talk, Building a Future 12-week program - focus on the carer
- MIFWA - carer didn't know she needed help until a peer support worker at Joondalup clinic referred her to MIFWA, she received peer support.
- Wanslea grand carers support group
- PMH/PCH, Eating Disorder Families Australia Strive group
- Peer Support is vital from people who have been on the same journey

What's not working well

Family carers were asked to tell us what they thought was not working well in the mental health and AOD service systems.

Carers universally spoke of a fragmented, siloed, poorly coordinated and inconsistent service system which causes them significant frustration, sadness, and anger. In addition, most carers shared experiences of when problems in accessing and maintaining services had resulted in negative consequences for young people and also for their own mental health as carers. Many carers spoke of 'revolving door' type situation, where they had been referred to different agencies then referred back to the original agency, with long waitlists and inconsistent information being provided by the various agencies. Transitions were described as particularly problematic, when a young person needed to go from one service to another, or because of age is moving from children to youth and then adult services.

Carers spoke of a 'postcode lottery' for services, particularly those in regional and remote areas—that the availability and quality of services was different based on where young people lived. Carers highlighted the lack of services for young people with complex conditions and comorbidities and the lack of coordination between services. They reported difficulty in accessing comprehensive information about the whole service system and also a lack of information about specific services. Carers reported experiences of 'siloed' services where young people with ADHD and Autism or AOD issues are not treated in the mental health system. They reported a gap in services between community-based services such as Headspace and Youth Focus and acute inpatient services, referred to elsewhere as 'the missing middle' (Hickie & Duckett 2020). Another critical gap in services highlighted by many carers was accessing acute and hospital care services for the 16 to 18-year old age group.

Carers reported repeated experiences of their young person needing to be critically unwell to receive services. They reported significant waiting times for services in both the public and private systems, community based and critical care services.

There was significant concern and disquiet about the lack of services for young people with eating disorders. Family carers of young people with eating disorders reported that they do not like the way their young people are often treated when accessing these services. Several carers described young people being treated as 'nuisances'. Carers reported that they do not like differences in treatment between different ages.

The quote from a carer below sums up the sentiment of carers about the problems that they have had in accessing and maintaining services.

'Not enough of anything.'

In terms of carer support services, the carers we spoke with were generally more positive, however some carers spoke about some key gaps in either awareness of these services or accessing specific services. Carers reported a lack of information about and the difficulty in finding services. Carers also reported that there is a lack of respite services to support them in their caring role

A summary of responses as they relate to services for young people and services for carers that family carers believe are not working well is outlined below.

Services for young people

- Services are not coordinated

- Services are not linked; they should be able to see records so young people don't have to tell the same story over and over or they will just shut up. Or lie.
- Services don't look at the whole person.
- Separate services for each illness.
- Young people with complex illnesses need lots of services.
- Young people need a crisis and/or a diagnosis to get services.
- Intake to CAMHS difficult, need to be really unwell
- Young people with eating disorders struggle to get hospitalised until critically ill
- Very difficult for people with anorexia and bulimia - to access services at PCH you need to be desperately ill
- Lack of information for serious illnesses, Services only available if you are really unwell.
- Services don't look at what young people need.
- Emergency response team needs to work better.
- Headspace etc. only deal with low level needs and are time limited. Also need community services with qualified staff to deal with complex and more serious illnesses. There needs to be something in between Headspace and hospital.
- There is more funding to depression and anxiety services, mental health support and less funding to chronic mental illness
- Stigma, judgement, parent blaming, parents seen as overreacting, parents seen as controlling, but it depends on which staff you get.
- Transitioning out of children's service into youth services is difficult
- Ridiculous waiting times for community services
- Having to spend long periods in the emergency department
- Some ED doctors don't understand self-harm and have no respect for the young person
- It took 10 months to get an appropriate referral, then 3 months to get an appointment
- MHERL not helpful
- Services need to take carers seriously and respect them.
- Services should involve carers and they don't
- Family Court issues about shared parenting/custody and mental health treatment being withheld without permission of one partner
- Postcode lottery
- Revolving door of clinicians
- The way staff in medical wards treat young people with an eating disorder

Services for carers

- One carer didn't know there were carer services until this consultation process
- Services need to come to you and meet you where you are at
- Need more services and more and better information about services
- Information about services is missing
- Need age appropriate groups
- Need respite services
- Headspace, Youth Focus and CAMHS won't talk to families, but carers need to be on the journey, there needs to be a balance between privacy and knowing things carers need to know.
- Difficult to find appropriate carer support services
- Should be a handout in ED to tell parents what to expect, what age services cover, referrals to services for carers
- No funding for carer peer support services in hospitals
- Carers don't identify themselves as carers, don't know to identify themselves as carers

Solutions

Carers had many excellent suggestions of possible service improvements. There was a recognition that more funding is required to address the issues of shortage of services and lack of inpatient beds, clinical and community services. Long waitlists at most services were mentioned as a key barrier to treatment and recovery. In addition, addressing the high costs of some private services with improved Medicare coverage was mentioned by many carers.

The ideas for improvement ranged from education and early intervention services to improvements in access for community based and hospital services. Carers suggested that education about mental health is important for everyone, particularly at school as part of the curriculum. This was seen as educative for all young people and also an opportunity to reduce the stigma of mental illness.

Coordinating and raising awareness of services was an area of improvement which most carers spoke about. They said that the complexity and siloed nature of the service system could be improved by better collaboration between services and removing barriers for more holistic services. For example, there was a strong interest for services that deal with both AOD and mental health services, with the same multi-disciplinary teams treating young people for co-existing conditions.

There was a strong interest in expanding peer support and lived experience services to assist both carers and young people. These services were highly valued by both carers and young people.

Carers told us that transparency and openness in services is an area for improvement. While carers understood the need for confidentiality and privacy in certain situations, they reported experiences where there has been unnecessary withholding of information and sidelining carers. Carers stated that they wanted to 'be brought along on the journey'.

Below is a list of service improvements suggested during the forums and one to one consultations:

- Mental Health Care Plans – we need more sessions
- Mental Health triage for initial assessment, and then referred to appropriate service. Central service phone or location or website
- More school based psychological and social work services are required
- Whole person care and assessment
- Child and youth-friendly clinical staff in hospitals, particularly in emergency departments
- Services for co-occurring needs - disability and mental health, substance use and mental health
- To be taken seriously as carers - carers to be involved and consulted
- Consistency and continuity of care
- Peer support service for young people and carers
- More peer support in mental health services for carers, to walk alongside the carer in services
- More youth beds in all inpatient services
- A specific inpatient unit for 16 to 18-year old's
- Induction session for carers new to caring
- Mental health response ambulance- outreach service
- Farm facility for rehabilitation
- Quiet place in ED for mental health patients

- Mental health training for GPs and nurses,
- Respite services so carers can do training
- Services should be promoted through the schools, communities
- Mental health education should start at school, also teaching people to recognise mental health issues
- Start young and teach young people about emotional literacy, done in some places, but is it done everywhere or continued during school
- Expansion of outreach services- once a young person has been discharged from a service or offering outreach instead of clinic services where possible

Case studies

The following case studies reflect the actual experiences of carers and young people in their care. They are designed to highlight some of the key issues for carers and young people described in this report.

One carer's unwell son is currently being held at Banksia Hill detention centre. He has been granted bail, but his father feels his son is getting better support and is safer in prison than he would be in the community. The father is waiting for a mental health plan from his son's treating team before he is prepared to pick up his son. He had no knowledge of any mental health carer support services before his involvement in this consultation process. He thinks that young people accessing mental health and AOD services should have their carers routinely referred to carer services. He also wants better integration and communication between agencies, and with carers. He wants much more emphasis on trauma informed care for his son.

One family's son presented to an emergency department after a recent suicide attempt. He was sent home from the hospital with no follow up or referral, however the police who attended the incident returned to carry out a welfare check with a team including a mental health clinician. The family have previous experience with the mental health system and are waiting for services in the private sector. They note that there are currently long waiting times to access treatment for young people from appropriate psychiatrists and psychologists in the private sector. They need clinicians with experience and training in trauma informed care.

A carer from a regional area has experienced difficulties getting treatment for her daughter with a diagnosis of anorexia nervosa. Their local GP had little knowledge of eating disorders and eventually the family had to present to an emergency department with their desperately unwell daughter. Their experiences with PMH/PCH and private services have been mixed. They believe that better education for GPs about eating disorders is essential. They also believe that clear guidelines for families caring for young people with eating disorders, and clearer protocols for dealing with any escalation of the disorder are necessary.

I received a phone call from my granddaughter at approximately 1pm on Wednesday. She was sobbing and distraught, saying she needed to go to hospital. I was close by and reached her quickly. She had taken a large number of pills, and I called an ambulance. She was taken to the emergency department and admitted for observation, given fluids and supplements to increase her blood pressure and blood sugar, as both readings were low, and she was dehydrated. A psychological assessment the following morning determined that she was not at immediate risk to herself and could be discharged into her own care with a follow up appointment with her GP recommended.

My 13-year-old daughter was accepted into an emergency program via CAMHS at PMH. This was an inter-disciplinary emergency intervention with intensive access to a psychiatrist, social worker, psych nurse and educator. She was an outpatient but was treated as an inpatient and the service was free, provided amazing support and lasted for about eight weeks. Truly amazing!

My granddaughter has a documented, diagnosed mental health condition. I repeatedly requested that the psychiatrist contact WAEDOCS, which is the consultancy service for clinicians in Western Australia, to determine appropriate treatment for her condition. The psychiatrist repeatedly told me she did not fit the criteria for an admission, and they would not contact them. There was nowhere safe and appropriate for her to be cared for, even for a short stay, to recover from an incident of serious self-harm. Once she was medically stable, she was sent on her way. I just wanted to give you a very timely illustration of the gap in our system. One of your questions was about what I would like to see for young people. I would have liked there to be some kind of sanctuary for her to spend a little bit of time to find her feet again. A gentle place to land and walk out feeling a little more restored. Instead we treat the medical symptoms and leave the emotional and psychological wounds festering.

A carer's 17year old daughter presented at Midland Hospital with suicidality, referred after seeking help from a GP. She couldn't be admitted to Midland because she was too young. Midland only admit people who are over 18. She is too old for PCH who only admit people under 16. There were no beds available at EMyU or FSH Youth Unit. After four days in the emergency department, coping because she thought she would get an admission, clinical staff thought she was okay, planned discharge into her mother's care while waiting for a bed in Perth Clinic. Daughter was fine with this as she had a plan and the means to kill herself at home. The mother removed the means of suicide and told her daughter what she had done. The daughter was upset and distressed by this and needed to be sedated. The result was that she wasn't discharged until there was a bed available in Perth Clinic.

The best that the establishment could do was give drugs to my daughter, an addict! She was pumped full of drugs at Fiona Stanley Hospital but when I suggested then should first test her for drugs in her system before feeding her more drugs, the doctor refused. "We don't do that here" she was suffering drug induced psychosis and substance induced mood disorders but was instead labelled with a long list of mental health diagnoses. Luckily, she has now been clean and sober for 12 months and off all psych meds and functioning well. It's just a shame the system put her through the wringer first. Now she is a participating member of AA and NA and not engaged with any other services. Yes, the doctors and big pharma and the p\$ychiatri\$t\$ would be sad they have lost a lifelong customer, but I got my daughter back! At age 20 she will soon celebrate one year clean and sober thanks to AA and NA.

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Appendix A: Online survey

Family Carer Survey

About this survey

Thank you for taking the time to complete this Family Carer Survey. The aim of this survey is for family carers of young people aged 12 to 24 to be able to share their opinions and ideas on current and future mental health and alcohol and other drug (AOD) services and family carer support services in Western Australia.

By Family Carer, we are referring to a family member, partner, or friend of someone who has used or plans to use mental health or AOD services, whose lives are affected by the issues affecting the young person.

What the project is about

We want to find out what the family carers of young people think about current mental health and AOD services in Western Australia. We want to hear your ideas about gaps and possible improvements in the services that are available for young people. We also want to hear your ideas about services or initiatives for family carers of young people using mental health and AOD services. We are collecting this information to present to the WA Mental Health Commission (MHC) which they will use to create a framework called the Young People's Priority Framework (YPPF). It is an opportunity to enact change and improve the system for young people and their family carers across the state.

What does participation involve?

This survey should only take 10 to 15 minutes of your time. Participation in this survey is completely voluntary. You can withdraw at any time without needing to give any explanation. If you decide to leave the survey before it is finished, we will not collect additional information from you, although information already collected will be kept to ensure that the results of the project can be measured properly. Information collected up to the time you withdraw will form part of the project results.

Your privacy

Information collected as part of this project will be kept confidential and will be de-identified. This means that your name and any other identifying information that you may include such as your suburb or names of services will not be used in any reports relating to this project. All data will be stored in a password protected file at YACWA and only those directly involved in the data analysis will have access.

Other information

This survey closes on Friday 16th October. If you would like to discuss the project, please contact Cathy on cathy@yacwa.org.au.

Family Carer Survey

About you

First we will ask a few questions about you. We are gathering this information to make sure we are including the opinions and experiences of a diversity of family carers.

1. How old are you?

- ☐ Under 18
- ☐ 18-24
- ☐ 25-34
- ☐ 35-44
- ☐ 45-54
- ☐ 55-64
- ☐ 65+

Comment

2. What is the postcode of where you usually live or the place you spend the most time?

3. How old is the young person you provide care for?

- ☐ Under 12
- ☐ 12
- ☐ 13
- ☐ 14
- ☐ 15
- ☐ 16
- ☐ 17
- ☐ 18
- ☐ 19
- ☐ 20
- ☐ 21
- ☐ 22
- ☐ 23
- ☐ 24
- ☐ Over 24

4. How long have you been providing care for the young person?

- ☐ Less than one year
- ☐ 1-4 years
- ☐ 5-10 years
- ☐ 11 years or longer

5. What is the postcode of the usual address or the place where the young person(s) you care for spends most of their time?

6. Which gender do you identify as?

- ☐ Male
- ☐ Female
- ☐ Non-binary
- ☐ Prefer not to answer
- ☐ Other (please specify)

7. Do you identify as any of the following:

- ☐ Aboriginal
- ☐ Torres Strait Islander
- ☐ Aboriginal and Torres Strait Islander

Comment

8. Are you from a refugee, migrant or multicultural background?

- ☐ Yes
- ☐ No

Comment

9. Are you living with a disability?

- ☐ Yes
- ☐ No

Comment

10. Do identify as lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual/agender (LGBTIQA+)?

☐ Yes

☐ No

Comment

Family Carer Survey

Your experience of mental health, AOD and family support services

We would like to find out more about your experience of using, or trying to use mental health and AOD services in Western Australia for young people that you care for. We are also interested in finding out about services or initiatives for family carers.

Mental health services for young people are things like school psychologists, counsellors and helplines. They may also be services such as Headspace, Youthlink or Child and Adolescent Mental Health Services (CAMHS).

Alcohol and other drugs (AOD) services for young people are things like counsellors, community programs, treatment centres and helplines. They may also be specific services such as Drug and Alcohol Youth Services (DAYS) or Palmerston.

Services and initiatives for family carers are things like parenting courses, counselling or helplines and may also be specific services such as Helping Minds or Carers WA.

* 11. Has the young person or people you care for used any mental health services in Western Australia?

☐ Yes

☐ No

If you answered YES to this question, please tell us the names and/or types of services that they used.

* 12. Has the young person or people you care for used any alcohol or other drug (AOD) services in Western Australia?

☐ Yes

☐ No

If you answered YES to this question, please tell us the names and/or types of services that they used.

* 13. Have you used services or initiatives for family carers to support you in your role?

- ☐ Yes
- ☐ No

If you answered YES to this question, please tell us the names and/or types of services that you used.

14. If the young person or people you care for *have not* accessed any mental health or AOD services, please tell us why? You can select as many as apply.

- ☐ We have not felt the need to access services
- ☐ We do not feel comfortable accessing services
- ☐ We do not know how to access services
- ☐ There is no service near where we live
- ☐ We get mental health and/or AOD support from other places (friends, family, youth groups, faith groups etc.)
- ☐ We get mental health and/or AOD support from the internet
- ☐ Other (please specify)

15. If you have not accessed any support as a family carer, please tell us why. You can select as many as apply.

- ☐ I have not felt the need to access services
- ☐ I do not feel comfortable accessing services
- ☐ I do not know how to access services
- ☐ There is no service near where I live
- ☐ I get support as a family carer from other places (i.e. friends, family, community groups, faith groups etc.)
- ☐ I get support from the internet
- ☐ Other (please specify)

16. If the young person or people you care for have used mental health or AOD services, please look at the statements below and tell us about your experiences. If the young person you care for has not used services, you can either tick N/A or skip this question.

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/A
The service(s) met my expectations	☐	☐	☐	☐	☐	☐
The service(s) responded well to my family member's mental health and/or AOD needs	☐	☐	☐	☐	☐	☐
The service(s) responded well to my family member's cultural needs	☐	☐	☐	☐	☐	☐

Comment

17. If you have used any family carer support services or initiatives, please look at the statements below and tell us about your experiences. If you have not used services, you can either tick N/A or skip this question.

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/A
The service(s) met my expectations	☐	☐	☐	☐	☐	☐
The service(s) responded well to my support needs	☐	☐	☐	☐	☐	☐
The service(s) responded well to my cultural needs	☐	☐	☐	☐	☐	☐

Comment

Family Carer Survey

Mental Health, AOD and family carer support services in WA

We want to find out about how well you think the mental health and AOD service system meets the needs of young people in WA and what supports are like for family carers.

We welcome your input into these questions even if a young person you care for hasn't used many or any services or if you haven't accessed support for yourself.

* 18. Please look at the statements below and tell us how you feel about these. The response options range from strongly agree to strongly disagree.

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
I am confident that I know where to find mental health and/or AOD services to meet the needs of the young person for whom I care.	☐	☐	☐	☐	☐
I think that mental health and/or AOD services in WA responds well to young people that have a range of different needs and come from a diversity of backgrounds.	☐	☐	☐	☐	☐
I think that there is good access to mental health and/or AOD services for young people in the area that I live.	☐	☐	☐	☐	☐
There is room for improvement in mental health and/or AOD services for young people in WA.	☐	☐	☐	☐	☐
I feel confident that I know where to find support for myself as a family carer	☐	☐	☐	☐	☐
I think that family support services for carers responds well to carers that have a range of different needs and come from a diversity of backgrounds.	☐	☐	☐	☐	☐
I think that there is good access to family carer support where I live.	☐	☐	☐	☐	☐
There is room for improvement in support services for family carers of young people in WA.	☐	☐	☐	☐	☐

Please tell us more about any of the above.

19. Which three words you would use to describe the youth mental health and/or AOD services and family carer supports in WA?

First word	
Second word	
Third word	

20. Tell us the three things you *most* like about the current youth mental health and/or AOD service system and family carer supports in WA?

1.	
2.	
3.	

21. Tell us the three things you *least* like about the current youth mental health and/or AOD service system and family carer supports in WA?

1.

2.

3.

22. We want to know about the gaps. Tell us what you think is missing from the current youth mental health and/or AOD service system and family carer supports in WA?

23. Tell us about any ideas that you have to improve the youth mental health and/or AOD service system and family carer supports in WA. This could include programs or initiatives that you think are running well or could be expanded, including those where you live or ones you have seen in other places.

24. If you were in Government and had the power to make decisions, what is the one thing you would do to make mental health and/or AOD and family support services better for young people and family carers?

25. Is there anything else you would like to tell us about your experiences with youth mental health and/or AOD services or family carer supports in WA?

Family Carer Survey

Thank you!

Thank you so much for taking the time to participate in this survey. Your responses will help us to make a better mental health and AOD system to meet the needs of young people.

Appendix B: Forum questions

1. What are the good things about current mental health/alcohol and drug services for young people, and current carer services?
2. What are the good things about current alcohol and drug services for young people, and current carer services?
3. What are some of the things you don't like about existing mental health/alcohol and drug services for young people, and carer services?
4. What are some of the things you don't like about existing alcohol and drug services for young people, and carer services?
5. Is there anything missing from existing services and systems? For young people and their family carers?
6. If you were in charge of funding services what one or two things would you do to make existing services different for young people, and family carers?
7. Is there anything else you would like to tell us about your experience of mental health and/or alcohol and other drug services for your family member?
8. Is there anything else you would like to tell us about your experience of carer support services?

Appendix C: One to one interview questions

1. Record demographic information
2. What kinds of things make a service/agency good to engage with? (prompt this could be about their office space, location, staff, or anything else you want to share).
3. Can you tell us about your experiences of accessing services, for your young person and for yourself? What worked well for you and what could be improved?
4. Have you ever tried to get support for your young person, and/or yourself and not received it? (prompt to share more about the experience if comfortable)
5. What are some of the things that might be missing in services at the moment? (prompt, both for young people and for yourself? Can you tell us more about that?)
6. What do you think the mental health system should look like in the future? What kind of services do we need?
7. What do you think the AOD service system should look like in the future? What kind of services do we need?
8. What should carer support services look like in the future? What kind of services would be helpful?
9. If you were the Director of Mental Health Services what would be the one thing you would change to make a difference for young people? What one thing would make a difference to carers?
10. Is there anything else you would like to tell us about?