

Alcohol and other Drug and Mental Health Cross Sector Forum

Summary Report
August 2014



Alcohol and other Drug and Mental Health Cross Sector Forum

10 June 2014

RISE Maylands

Summary Report

Prepared for WANADA and WAAMH members, consumers, family members and significant others and carers who access services in the Alcohol and other Drug sector or the community managed Mental Health sector.

Report prepared by WANADA



Suggested reference: Alcohol and other Drug and Mental Health Cross Sector Forum Summary Report (August 2014) Western Australian Network of Alcohol and other Drug Agencies (WANADA). Perth, Western Australia.

NOTE:

This report is a summary record of a Cross Sector Forum convened by the Western Australian Network of Alcohol and other Drug Agencies (WANADA) in collaboration with the Western Australian Association for Mental Health (WAAMH). The Cross Sector Forum was held on 10 June 2014 at the RISE in Maylands and invited participants included equal numbers of service providers, consumers, family or significant others and carers from across the two sectors. The Cross Sector Forum was facilitated by Professor Margaret Hamilton. This report captures the main points from the group discussions as recorded by a nominated small group scribe/facilitator allocated to each of the groups. This report does not contain a verbatim transcript of all issues discussed, and attempts not to embellish, interpret, or enlarge upon matters that were incomplete or unclear. Some sections do include a summary of the discussions by the facilitator Professor Margaret Hamilton.

ABBREVIATIONS

| | |
|--------|---|
| AOD | Alcohol and Other Drugs |
| CoMHWa | Consumers of Mental Health WA |
| DAO | Drug and Alcohol Office |
| MH | Mental Health |
| MHC | Mental Health Commission |
| NSEP | Needle and Syringe Exchange Program |
| WAAMH | Western Australian Association for Mental Health |
| WANADA | Western Australian Network of Alcohol and Other Drug Agencies |
| WASUA | Western Australian Substance Users' Association |

TABLE OF CONTENTS

| | |
|---|----------|
| 1. BACKGROUND | 1 |
| 1.1 Historical context: | 1 |
| 1.2 Current context: | 1 |
| 2. METHOD | 2 |
| 2.1. Purpose and Aim of the Forum: | 2 |
| 2.2 Key forum participants: | 2 |
| 2.3 Forum Format | 3 |
| 3. FORUM SUMMARY | 4 |
| 3.1 Session One: Expectations and Service Values | 4 |
| 3.1.1 Expectations | 4 |
| 3.1.2 Service Values | 7 |
| 3.2 Session Two: Commonalities and Differences across the Two Sectors | 8 |
| 3.2.1 Commonalities: Summary of Key Themes | 9 |
| 3.2.2: Differences: Summary of Key Themes | 10 |
| 3.3 Panel Discussion | 13 |
| 3.3.1 Maintenance | 15 |
| 3.3.2 Peer Support | 15 |
| 3.3.3 Recovery | 16 |
| 3.4 Future Directions | 18 |
| 3.4.1 WANADA and WAAMH Commitment Statements | 18 |
| 3.4.2 System Wide and Cross Sector Consideration | 20 |
| Appendix A - Cross Sector Forum Reference Group Terms of Reference | 22 |
| Appendix B - Summary Cross Sector Forum Evaluation | 23 |

1. BACKGROUND

1.1 Historical context:

Increasingly the Alcohol and other Drug (AOD) and the Mental Health (MH) sectors in WA have been working more collaboratively, recognising that for many people accessing services across the sectors, co-occurrence of mental health concerns and issues related to AOD use are not uncommon and can be burdensome affecting individuals, families, and public health.

Competing historical paradigms of mental illness and issues related to AOD use may present a barrier to progress and be an impediment to care. People easily fall into the cracks between mental health and AOD services. Clinicians feel untrained and consumers bear the brunt of this: Judgmental and moralistic interactions persist and comorbidity is unrecognised in high-risk populations.

The relative value placed on lived experience in the AOD field and mental health paradigms produces a fundamental philosophical conflict among models of care. Differences in conceptualization, epistemology, and treatment philosophies remain a barrier.

However, lack of communication, fundamental philosophical approaches, division of service provision, systems that can be antagonistic or contradictory, and disparate funding structures all limit cooperation and collaboration and generate “roundabouts” in Australia and internationally.

1.2 Current context:

Both the Drug and Alcohol Office (DAO) and the Mental Health Commission (MHC) have been undertaking consultation with the sectors to support the development of the 10 year plan for both sectors. The plan will act as a ‘blueprint’ for the optimal mix of services needed to provide a better, more responsive and more equitable mental health system and to guide the provision of AOD prevention activities, and treatment and support programs and services in Western Australia.

During this and numerous other consultations within the sectors, language and terminology has been identified as an issue that needs to be discussed between the two sectors, to enhance awareness, respect and appreciation for common intent, and to increase understanding.

At a meeting in December 2013, with the then Mental Health Commissioner Eddie Bartnik, and the Executive Director from the DAO Neil Guard endorsed the proposal to hold a Cross Sector Forum. They believed the Forum would provide the opportunity to consider understandings of core principles and values of both the AOD and Mental Health sectors, what the sectors share in common and what potential points of difference may be. A key objective of the forum would be to explore terminology used by both sectors with the aim of reducing stigma, guided by

evidence and consumer input. It was also agreed the Forum could be the beginning of a series of events, the beginnings of the conversation.

2. METHOD

Subsequent to the meeting held in December 2013 and a following meeting between WANADA and WAAMH key personnel in January 2014 it was agreed that a Cross Sector Forum Reference Group be established with equal representation from the AOD and the community managed Mental Health sector, consumer representatives, and family carer representatives. The Reference Group members met 3 times during April-May 2014 to progress the aim and format of the Forum (Terms of Reference were agreed and can be found in Appendix A).

2.1. Purpose and Aim of the Forum:

To promote relationship building and understanding between the sectors, the format of the forum needs to allow space to explore and spend time sharing views. It was agreed that the forum needs to be in an inquisitive format with consultation at all levels.

The aims of the Forum are to:

- Enhance understanding of core principles and values of both the AOD and MH sectors
- Increase awareness of the similarities and difference across the two sectors, including a clearer understanding of the different meanings of similar language and terms used.
- Explore terminology used in both sectors with the aim of reducing stigma, guided by evidence and consumer input
- Support and promote improved relationships, understanding, collaboration and partnerships between the AOD and MH sectors, consumers, carers and family members.

2.2 Key forum participants:

To support equitable and inclusive processes between the two sectors, consumers, carers and families it was agreed by the Reference Group that there needed to be balanced representation of the following:

- 15 AOD consumers
- 15 MH consumers
- 15 AOD family members
- 15 MH family/carers
- 15 AOD service providers
- 15 MH service providers

In selecting participants, consideration and representation will be given to Aboriginal, CaLD, young people, regional/rural/remote representatives; and an appropriate mix of government and non-government service providers. It was agreed that WANADA and WAAMH would take responsibility for inviting their respective sector participants to the Forum.

WANADA asked service providers to invite consumers, family members and significant others as the service providers had the relationship with these groups. Consumers and family/carers were remunerated for their participation.

WAAMH's process for engaging with consumers and carers was to invite consumer and carer representation through its networks, which include Consumers of Mental Health WA, Mental Health Matters 2, Arafmi, Carers WA and others. All consumers and carers were remunerated for their participation.

Participants were provided with brief background document, which included the aims of the Forum. This was sent with the invitations. A number of key stakeholders and peak body (WANADA and WAAMH) staff also attended.

2.3 Forum Format

Preparation for the Forum included producing video interviews with an AOD and MH consumer, a Mental Health family member and an AOD and MH service representative. Permission and consent to include the information contained in the videos was gained from each participant. The full interviews were edited to provide a variety of perspectives from the 5 participants. The purpose of the short videos was to prompt discussion for Session One and Session Two during the Forum.

Video participants were asked the following questions:

Consumers and family members/carers of AOD/MH services

- *What do you feel you have in common with consumers from the other [AOD/MH] sector?*
- *What is your understanding of the commonalities between the two [AOD/MH] sectors?*
- *What is your understanding of the differences between the two [AOD/MH] sectors?*

Service Providers of AOD/MH services

- *What do you feel you have in common with service providers from the other [AOD/MH] sector?*
- *What is your understanding of the commonalities between the two [AOD/MH] sectors?*
- *What is your understanding of the differences between the two [AOD/MH] sectors?*
- *The importance of partnerships/shared care with services from the other [AOD/MH] sector for better outcomes?*
- *What makes the partnership/shared care work to achieve these outcomes?*

The Forum was held on 10 June 2014, 8:30am – 4:30pm at the RISE. The Forum commenced with an Acknowledgement to Country and was opened by the Hon. Helen Morton MLC, Minister for Mental Health, Disability Services and Child Protection.

The Forum was facilitated by Professor Margaret Hamilton and was structured into 4 distinct sessions throughout the day. The topic of each session is outlined below:

Session One: Expectations and Values: Strengthening service and consumer/family member understanding

Session Two: Commonalities and differences across two sectors: A clearer picture of two sectors

Session Three: Language and Terms: Multiple definitions, Common Understanding

Session Four: Resolutions and ways forward

Ten tables, ideally with one representative from each of the key forum participant categories, were orchestrated at the commencement of the forum. Each table had a nominated facilitator, who would also scribe the discussion and be the primary spokesperson, providing feedback to the larger group following small group discussions.

3. FORUM SUMMARY

The following section will provide a summary of the group discussions and panel discussion held over the course of the day.

3.1 Session One: Expectations and Service Values

As an introduction to the day, Professor Hamilton asked participants to indicate with a show of hands if they knew someone, were themselves or were a family member of someone who had experienced problems related to their use of alcohol and other drugs or had concerns related to their mental health. All participants raised their hand and Professor Hamilton noted that all participants therefore had a personal experience that would be valuable in relation to the discussions of the day.

Professor Hamilton also asked that participants remain open to listening and not to react to the different interpretations of language offered by fellow participants.

Following a viewing of the first video, Professor Hamilton invited each table of participants to discuss expectations of service values. The consumer and family members were asked to discuss their expectations of how their needs will be met by an AOD/MH service. The service providers were asked to discuss what key values underpin the service they provide. Professor Hamilton asked each of the groups to consider similarities and differences.

3.1.1 Expectations

During discussions it became clear that the level of expectations of what services would provide were similar across both sectors.

First point of contact - No Wrong Door

The initial connection or first impressions were noted as being foundational in the consumer or family members' experience of a service. Consumers and family members are seeking quality support and assistance in a non-judgemental manner that displays respect, empathy and compassion. This could be translated with an approach that the service provider is walking with/alongside, providing professional support. From a consumer or family member perspective it was important that the values of the organisation were clearly demonstrated or put into actions.

"It doesn't matter where the consumer presents but the response would be the same."

The expectation is to be seen as a whole person and for both MH and AOD to be acknowledged and responded to and all aspects of a person's life are addressed.

One consumer commented that being asked *"what is happening with you, not what's the matter with you"* is an approach that communicates the message of seeing the person and not the problem.

A comment by an Aboriginal participant noted *"Aboriginal people accept MH issues in their people and MH isn't always seen as a first priority rather things like housing, safety, money and food were seen as more important and services should be aware of this"*.

When discussing a holistic approach, consumer and family representatives also commented on the importance of treating everyone as individuals,

"recognising the journey may not be a smooth path and having realistic expectations for and of consumers throughout the treatment and support process is fundamental to consumer wellbeing"

Consumer Involvement- Family Inclusion- Confidentiality

Consumer involvement in all areas of services was also discussed, consumer expertise needs to be recognised for the benefit it can provide to treatment and service progression.

"The consumer voice in how services are designed needs to be valued and listened to".

Some groups felt the idea that consumers are the passive recipients of services needs to be resisted, consumers would expect to have a voice and consumer rights and responsibilities need to be made clear.

"The consumer is the expert of their own life and the service provider will gain benefit from consulting with consumers with an inquiring approach".

A further expectation expressed was that services would recognise the importance of family inclusion. The benefits of including family from the beginning were highlighted.

“After receiving consent from the consumer, initiate communication with family members and not just have family participation as an add-on”.

After these initial discussions participants acknowledged the importance of family/carers being able to access their own support services.

Following on from family inclusion, confidentiality was discussed. The underpinning component of confidentiality expectations was the need for informed consent and the consumer giving permission for what information is shared and with whom. Families expressed the need for exploration of this sharing of information and some groups raised the point of services needing to communicate and collaborate with each other for the benefit of the consumer.

“Services need to communicate with each other, but need to absolutely consider consumer confidentiality”

Access to Services- Inclusive Services

Participants from across both sectors acknowledged the advantage of services having strategies in place to support the consumer and family members if immediate provision of service is not available. The importance of maintaining and supporting engagement was highlighted at this point with the view that entry/exclusion criteria can leave some consumers/families vulnerable.

It was noted *“that during the referral process, re-telling your story can be traumatising and cause consumer fatigue”*. The approach of the service provider *“listening with genuine interest is paramount to reducing the stress”* associated with this.

Further to the discussion of access and inclusion, expectations across both sectors were that there is a consistent level of access to services regardless of geographical boundaries.

“People need to recognise there is limited access to a diverse range of culturally appropriate services in the remote communities”.

Consumer and family members highlighted the need for services to be inclusive of Aboriginal and Torres Strait Islander (ATSI) and Culturally and Linguistically Diverse (CaLD) peoples. It was acknowledged that this inclusive approach would entail services having culturally appropriate staff.

Participants commented *“service providers need to recognise that sometimes a power imbalance is evident that impacts on the cultural security of the service being offered”*.

Community Attitudes - The human approach

Consumers and family members raised the concept of community attitudes and stigma. A comment from a forum participant highlights

“stigma can come from other consumers, or from some service providers, with the problem being considered a person’s fault rather than looking at it as a continuum”.

The expectation from this discussion was that a community education approach may reduce some of the stigma that is associated with both MH and AOD, with one group stating this will only occur with *“appropriate engagement with the community”*.

Consumers expressed service providers need to *“move away from diagnostic labels and medication”*. This approach would assist in *“recognising the real human experience and as a service provider you would not be seen as attempting to prescribe someone’s recovery?”*

Consumers identified that *“they don’t want, or need fixers”* and just because *“service providers have done it a certain way, it doesn’t mean it needs to continue in that way”*.

Perseverance and resilience were words expressed by some groups that portrayed a level of expectation of the consumer and family members across both sectors. A comment from one group summarises the approach service providers could take to ensure the human approach is translated across all of the services

“think of the person you love the most and ask your staff, would this service be good enough for them?”

3.1.2 Service Values

As service providers contributed to the discussions, it was clear the service values across both sectors were similar. The differences that were noted were more to do with funding, resourcing and the presence of government and NGO services in each of the sectors.

“MH sector has a larger public mental health service with much less NGOs in this sector this seems to be opposite to the services in the AOD sector”.

One comment from a service provider *“workers need a set of values to work effectively”* displays the intent of the values the service providers aspire to display. Some words used to describe these underpinning values were support, kindness, acceptance, dignity, respect, trust, integrity, compassion, consideration, hope, care, a non-judgemental approach and empathy. Service providers expressed the necessity to display a level of humanity through recognising the need to understand each other and providing health treatment without labels.

“understanding what a service is, and what it does” is key to providing quality service for consumers.

Service providers acknowledged the benefits of a holistic approach to consumers’ needs.

“Building the capacity of the workforce” and providing training to increase staff understanding of the approaches to AOD and MH enables services to continue to “provide a professional service that offers a level of expertise and progressive understanding”.

A further value identified by service providers was the aim of providing self-determination and empowerment for the consumer.

Groups felt “ways this may occur is by having the consumer as the first priority, by developing trust and rapport through effective communication”.

The overall aim of the service provider was acknowledged as *“helping people to be the best they can be”* this aspirational approach enhances positive outcomes for the consumer.

Service providers recognised the advantages of collaboration and mutual respect across sectors with the consumer benefiting from a shared clinical care approach.

“cross sector service awareness enables transfer of knowledge across fields of expertise”.

Service provider discussions included the intent of services to provide equitable services at all levels, *“being community aware and being prepared to go to the people”* was recognised as an important value of an inclusive service.

“Thinking outside the square for individuals” and “taking a creative approach” was noted as being an important component of providing an inclusive service.

Included in the discussion related to access of services was the need to offer different choices of the type of service provided. Accessible language was a further consideration noted for the provision of an inclusive service.

“This not only appreciates English as a second language but also medical/sector jargon that may be used throughout the consumer experience”.

Recognising funding models need to be adaptable was central to this inclusive approach.

3.2 Session Two: Commonalities and Differences Across the Two Sectors

Consistent with the format of Session One, participants viewed a video clip with consumers, family members/carers and service provider representatives providing their thoughts to the following questions: What they felt they had in common with their counterparts from across sectors, and what their understanding of the commonalities and differences between the two sectors were. The two service provider representatives also articulated their views on the importance of partnerships/shared care between the two sectors and in their view what makes these work.

Following the video, Professor Hamilton invited each table to discuss these questions and to also consider the importance of partnerships/shared care for better outcomes for people who are accessing services.

3.2.1 Commonalities: Summary of Key Themes

A number of key themes emerged from the feedback that revealed an understanding of commonalities within and across the sectors.

Many consumers and family members felt there was **stigma** associated with having problems related to both their use of AOD and or their MH concerns:

“an AOD user won’t access services because of an association with mental health and in the case of a person with concerns around their mental health they won’t access AOD services”.

This was reinforced by one group’s feedback:

“Consumers have a preference to be identified as either ‘druggie’ or ‘crazy’”

Some groups felt what was common was many people accessing services had **both issues** related to their use of alcohol and other drugs and concerns with their mental health and wellbeing. Others noted that **“comorbidity”** was not the exception rather the **“expectation”**. This was consistent feedback, with comments such as:

“Common clients and families”, “Alcohol and other drug use and mental health concerns tend to be interdependent issues” and therefore there is a need for a “holistic approach that includes physical health and to take time to hear the whole story and see the whole picture “

However, other groups were keen to make the point that *“not all people accessing services in one sector have the other condition”*.

It was also acknowledged that generally services in the two sectors are *“person centred”*, and tend to both come from a *“psychosocial framework”* with the **common goal** of providing help and support. One group felt that the commonality between the two sectors was:

“Intrinsically they value the humanity of the people they serve” and that the “Individual is recognised in their social context”. “We all have words or ways of describing a journey to a meaningful life with personal agency”

Some groups felt there were **areas for improvement** in both sectors. For example, it was noted that the *“use of labels”* tended to be common in both sectors, and that consumers and family members/carers may *“not always experience the best outcomes”* from either or both sectors.

“Healing and connection to spirit is lacking in both sectors” while others felt “neither sector engages well with families”. It was also noted both sectors tend to “have a lack of consistent data collection for CaLD groups”.

Continuing on this theme, groups noted areas for improvement that tended to impact at a **service system** level, including the following observations:

“There is a requirement for enhanced partnerships with government agencies across the sectors and other government agencies and with each other”.

This notion was reinforced with a number of groups noting the continued

“Siloing between NGOs and government services”.

A recurring theme throughout the forum was the issue of language and this was noted as a commonality between the two sectors with both *“struggling with the language”* of the other.

And finally one group noted that they believed what was common in both sectors was *“the difference between the words/values and the behaviours of service providers in each sector”*

A number of groups also acknowledged that both sectors were *“highly skilled”* but also that they were being adversely impacted by *“reducing and insufficient resources”*.

In relation to common themes around **models of care** the following points were noted: Both sectors were required to implement *“evidence based practice”* and appeared to be able to offer a *“Suite or spectrum of options”* and this was viewed as the sectors being able to provide a *“holistic approach”*.

Groups also noted there was *“emerging recognition of families, carers and consumers”* across both sectors, while others felt the *“peer workforce was making a difference”*.

Interestingly, the 10 groups were able to identify a range of commonalities and the majority of these tended to be encapsulated in the themes identified above.

3.2.2: Differences: Summary of Key Themes

All groups were able to identify some distinct differences between the two sectors these are outlined below.

It was very evident that there are vast differences between the **amount and nature of services** provided by Government and non-government services within the two sectors.

Within the AOD service sector approximately two thirds of the total annual funding budget is allocated to services provided by NGOs. This contrasts significantly with the mental health sector where approximately 87% of the annual budget is allocated to Government delivered mental health services. Some comments on this difference included:

“In the mental health sector, clinical and community based service provision are separate” and further “Given the size of the NGO (community managed) mental health sector, standardisation of service provision is very expensive”

“In the AOD sector clinical care is provided by both Government and non-government services” and “there are examples of NGOs working with Government services to provide an integrated service, managed by the NGO, which works better for service users”

A number of groups provided examples of the Integrated Services working in practice in the AOD sector, noting that the integration of two services proved challenging initially:

“This required two different cultures being respectful of the value of each other and having real clarity about the need and roles for both services in this integrated model”.

Many groups identified differences between the ways services are provided or the **models of care** within and across the two sectors. Notably there were many groups who described their views about the historical context of service provision and the implications of this. In relation to the mental health sector the following observations were made:

“The medical approach in mental health is driven by psychiatry” and as a consequence some believed that ‘this creates a power imbalance that is difficult for consumers’. One example was around side effects of prescribed medication, “Expert recommends ‘keep going with medication’ when the consumer perceives the medication is “creating more issues”.

There was also recognition by many groups that MH services were guided by requirements of the Mental Health Act.

“often services are provided as a Legal response and there is potential for enforcement if you are unwilling to seek treatment”. In addition a number of groups noted the medical response to mental illness requiring the individual to be compliant with the recommended treatment with “threats to ongoing participation in a program”.

This contrasted with other feedback that indicated some groups felt that mental health services

“support people to get their life back” where the “individual is in control” the focus of support was “about the journey” and this was “empowering”.

A number of groups also felt that some mental health services *“won’t take people who are actively using AODs.”* While others noted *“alcohol is sometimes seen as self-medication for mental health issues and is more acceptable”.*

While others commented on a lack of consistency to addressing AOD related issues in the mental health sector *“assessment of and addressing AOD related issues in the mental health sector depends on the service”*.

The differences in the AOD sector observed by most groups was the **models of care**. The AOD sector operated primarily from a Psychosocial Model.

“There is a bigger focus on a non-medical approach” in the AOD sector with *“pharmacotherapies used to support functioning”*.

Groups commented that the AOD sector also had a *“harm reduction philosophy”* and included *“early intervention”* and therefore felt the approach was more *“holistic”*.

A number of groups suggested the *“AOD sector can recognise ‘undiagnosed’ mental health concerns compared to mental health services needing a clinical diagnosis”*.

“Client motivation is important in the AOD sector and relapse is not unexpected”. Many felt *“AOD treatment is more voluntary”* while acknowledging *“Some clients are court ordered, but this is a justice requirement and not an AOD sector requirement”*.

Conversely some groups felt the approach to treatment for problematic AOD use was an *“insistence on abstinence”* and this meant there was some *“level of judgement”* about continued use. One group felt that this meant treatment was approached as having a *“finite or end point with a punitive approach if you don’t succeed”*.

Another difference in the nature of service provision was highlighted by the following comment:

“AOD rehabilitation treatment is paid for by clients; with mental health rehabilitation treatment it is less common for clients to pay”

Some feedback indicated there is a level of misunderstanding about the AOD sector. This was highlighted by the following comments:

“the AOD sector has come from the self-help movement and this is what the community based NGOs offered in the sector”

“In the mental health sector most workers have degrees but in the AOD sector most workers have TAFE qualifications”

Stigma associated with AOD use was also identified by some groups.

“Mental Health is not self-imposed and therefore people have more forgiving attitudes to those with mental illness”.

“Differing community perceptions of the level of blame/culpability”. “AOD users are given sympathy when there’s a traumatic (childhood) story” but when this

was not evident they are “*blamed for their circumstances*” and not “*deserving of treatment*” rather they should “*just pull your socks up*”.

Again, the importance of **language** was highlighted when groups provided feedback on their perceived differences between the two sectors. Specifically it was noted that:

*“AOD **recovery** is based on 12 step model which is abstinence based while mental health recovery is a normal state of health”*

What became evident from the many comments on language differences fed back by the groups is captured well in the following comment:

“there are very different interpretation of many words and a lack of knowledge of this across sectors”.

One group felt “*AOD is a mature sector*” and is “*creative and nimble*”. While another group stated “*AOD is far more holistic and humanitarian – MH chops the brain from the body and personal needs*”.

Finally one group simply stated they felt a major difference between the two sectors was primarily around “*language and misunderstanding of each sector in many ways*”.

3.3 Panel Discussion

Professor Margaret Hamilton facilitated the panel discussion. The panel was comprised of Monique Williams, CEO Mental Illness Fellowship of Western Australia (MIFWA); Carol Daws, CEO Cyrenian House; Louise Grant, CEO Western Australian Substance Users’ Association (WASUA), Margaret Doherty MentalHealthMatters2 (MHM2) and Carli Gettingby, Mental Health Consumer representative.

The aim of the panel discussion was to explore language and terms, increase understanding of multiple definitions and recognise common understandings. The complexity of language and understanding of the meaning of words across sectors was further highlighted during this session of the forum. Not only can one word have different interpretations across both the MH & AOD sectors, but it can also have different meanings within the sectors. Each of the panel members was asked to explain what they understood from words or different terms. Professor Hamilton then opened this up to the floor and forum participants were able to contribute their thoughts and ideas on what different terms meant to them. Below is a summary of these discussions.

3.3.1 Maintenance

AOD Sector

When asked the question what does maintenance mean to you? In the AOD sector maintenance is understood to have several meanings. The first interpretation of the word was described as a pharmacotherapy evidence based program. This was explained as the replacement of a person’s drug of choice with a legally prescribed and dispensed substitute. The aim of the maintenance program is to stabilise drug

use and reduce the potential harms from using illicitly. Many find this allows more time to manage their lives. This was generally viewed as a positive program, but there were some negative aspects related to how the program was administered in WA, these included the following comments:

“For consumers there can be punitive issues if they are non-compliant and continue to use other drugs illicitly”.

Cost and poverty were further issues raised when discussing the pharmacotherapy program in the AOD sector. This included some issues with the availability of enough administering chemists and the

“de-humanising experience” associated with “presenting daily for a measured dose of medication to be taken under supervision”.

A further meaning of the term maintenance was explained as the AOD sector using this term when referring to one of the Stages of Change model. This model recognises different consumers may be at different stages in their motivation to make and maintain change in their life, to use more safely, reduce or stop using AODs. Maintenance is used to describe the fifth stage of change in this model.

MH Sector

For the mental health sector the term maintenance can refer to ensuring a consumer is medication compliant. When discussing this term MH representatives explained that the quality of life is not regarded as part of the maintenance process.

Maintenance in the MH sector refers to medication compliance with disregard for a person’s happiness.

This word generates the idea of *“necessary but not sufficient”*.

Maintenance was also described to be the *“antithesis”* to recovery in the mental health sector. It can be understood to mean maintaining people in their illness. A further comment from the mental health sector:

“the term doesn’t fit into the health system, it should be chucked out of the health sector completely”.

Maintenance can also refer to the family responsibilities of maintaining aspects of a person’s life such as house, gardens, pets, when that person is in treatment.

Maintenance can also relate to maintaining good relationships, contributing to society,

“things you have to do to maintain your place in society” and “sometimes takes the place of the word recovery, but has less hope and is not an aspirational word”

Facilitator

On reflecting on the discussion relating to the term maintenance Professor Hamilton surmised in general terms, in the AOD sector maintenance typically refers to a replacement pharmacotherapy program that is supported by sound evidence of improved outcomes for those in the program, while in the mental health sector it is not an immediate therapeutic approach, which may in fact have a negative impact on a person's ability to recover.

3.3.2 Peer Support

AOD Sector

Views expressed by the AOD sector participants when asked to define the term peer, peer worker, peer support included an explanation that this word has many applications and meanings in service models, service provision and has different meanings for different people.

Some of the comments encompassed *"a variety of styles of peer workers"* acknowledging *"one size doesn't fit all"*, and others asked the question, *"why do we need a framework to limit peer support? - we need diversity."*

The benefits of peers or peer workers was touched upon when one participant mentioned *"there is a huge gain of knowledge from peers"* and access for clients is increased through peers, Needle and Syringe Exchange Programs (NSEP) were given as an example. There is a role for peers in all aspects of the work the sector does and we should be offering a menu of responses.

Two further points raised was the concern on the recent focus of attention being on whether the person is fit for their role rather than what the person is or has experience with. *"Peers in the AOD are increasingly being defined by abstinence"*, *"there is a danger of peers being seen as worthwhile only when they are paraprofessionals"*.

Some panel members also commented the power balance is not always equal and the peer worker approach is not an opportunity for a *"cheap workforce"*. Comments also included the *"need to acknowledge the level of stigma attached to being a peer"* and *"the importance the right training and supervision too"*.

Some examples of peer workers or support groups were identified, including a *"parent peer support group that works really well"*.

MH Sector

When discussing peers and peer workers the mental health sector participants acknowledged peers and peer workers provide an aspect of self-help and mutual aid paired together.

"Peers are essential", *"a powerful strategy"* in providing underground knowledge and access to services to reduce angst for current consumers.

Peers can be *“someone who has been there before, just walking alongside”* to encourage and support the consumer to continue their own journey. The consumer feels a sense of being understood. Peers can provide cultural support and relevance.

From a family to family experience participants advocated the value of peer support offered through this avenue. One person commented the understanding of peers being on the same page and being able to share *“delightful ‘black’ humour”*.

Similarly to comments from the AOD sector, participants at the forum representing the MH sector commented on the *“concern or risks of peers only being acceptable when they are seen as paraprofessionals”*.

Facilitator

From listening to both sectors sharing their understanding of the term peer or peer worker Professor Hamilton acknowledged the role of self-help and mutual aid that peers offer. She noted there is a place for peer support on our repertoire or menu of approaches to support people accessing services that includes the right training and supervision to ensure wellbeing.

3.3.3 Recovery

AOD Sector

The views expressed by the AOD sector representatives indicated there were varying degrees of discomfort with the use of this term. The word recovery has multiple definitions and can evoke strong reactions from different people. There was a difference in interpretation of the word between consumers and service providers.

One consumer comment highlighting this *“I saw the word as a great thing it gave me hope and then I left treatment”* another consumer comment *“recovery was never used by the clinical team once”*. Depending on the personal belief of the individual some people may not be willing to use the word recovery and instead may state *“today I am abstinent”*.

Historically in the AOD sector the word recovery has been used as part of the abstinence or 12 step program originating from the temperance or Alcoholics Anonymous movement. The use of this word applies pressure and sometimes judgement and as such is seen negatively by some people in the AOD sector.

For this reason one participant comment was *“don’t want to see this term used in the 10 year plan in AOD or MH”*.

A further comment coming from panel discussion relating to the word recovery:

“you need to ask the question, what are you recovering from? For those who don’t have AOD/MH in the community who also want a good life; are they on a journey of ‘recovery’?”

This comment also raised the point that people are viewed as *‘not recovered’* if they are choosing to continue to use AOD.

Further discussion raised the issue of why we have to have language that is all the same. It also was acknowledged that we might make assumptions about what certain words mean to other people, and this might mean we are placing our values on others.

“Why do we have to be so conformist”, “we may be forcing people to accept a word they may not be comfortable with”

MH Sector

Like the AOD sector the term recovery in the MH sector has many meanings.

Based on the New Zealand blue print one definition of recovery is *“living well in the absence or presence of mental distress”* this would encompass multiple levels of recovery. One consumer comment highlights *“what underpins the language is more important than the language itself”*.

“Historically the word recovery came from the psychiatric survivor movement in the US, where the intent was to describe people surviving the MH system”.

One interpretation is *“being given the opportunity to live a good life”, adding “it creates positive identity and what I want”*.

It was noted, in WA when developing the 10 year plan rehabilitation was removed from the plan and replaced with recovery.

From a consumer perspective it is *“service language”, there are “different definitions of recovery but this is not what I come in the door with”* in saying this the consumer then went on to explain language is important because it, *“changes way we are perceived, it allows communication between consumer & medical profession this can be a positive thing as many “MH labels are destructive”*. De-medicalise the vocabulary as much as possible *“it is about finding common ground”*.

Further discussion of the understanding of the word recovery within the MH sector provided insight that there is value in the word, the notion of recovery may give consumers, carers and families

“hope for a good life”, “it is not about cure, it is about journey and process”, there are many levels of recovery “it is a continuum that may last throughout your life”.

Recovery should be left to personal recovery, *“it shouldn’t be over-defined or it will impose our values on others”*.

Facilitator

In summarising the overall panel discussion session Professor Hamilton explained from the dialogue it is evident there are different understandings of terms and words and they have different histories and origins. She noted, it was also clear that as

people have listened they have been less sure of their own position, they have had to reframe and rethink.

“We think we know the history and origins of word, but the more you listen the more you realise the diversity of meanings”.

She also identified that words and their meaning change over time. An example she gave was from the AOD sector, the use of the word ‘disease’ of ‘alcoholism’ was originally seen as good whereas now it’s not. Now it is recognised that the use of this term has negative moral overtones and proffers a judgement that is not helpful. Noting that *“often if we ‘blink for a while’ the implications of words will change”*.

Professor Hamilton also emphasised it is important to recognise people can be impacted by the words we use, and we may not always be coming from the same place. For some, particular words are constructive and progressive whereas for others the same word is detrimental. It is also important to note some language is service language and has no meaning for the consumer. To conclude her comments on language and terms and diversity of meanings and understandings Professor Hamilton reminded the forum participants of a comment made from a consumer during these discussions that *“the term is not important to me, but what is important is the values shared”*.

3.4 Future Directions

The format for the final session was the same for session One and Two. Groups were asked to discuss the way forward from all the discussions they had and heard over the day. Below is a summary of the key priority areas identified.

These have been presented as WANADA and WAAMH commitment statements, where the priority areas focused on activities/strategies that are within the remit of the two Peak Bodies to progress.

Where the suggested resolutions/key priority areas were outside the remit of the two Peak Bodies, these have been drafted as recommendations for consideration by external key stakeholders.

3.4.1 WANADA and WAAMH Commitment Statements

Commitment Statement 1: To build recognition of common ground and difference in expertise and language between the two sectors

The main suggestions from feedback focused on the importance of WANADA and WAAMH continuing to work collaboratively, however a number of groups also outlined what they felt was essential to the quality of the ongoing collaboration.

“WAAMH and WANADA to continue to work collaboratively but to also be protective of each other’s expertise and role”. Further comments outlining the nature of the collaboration between WANADA and WAAMH stressed that the organisations *“reach a space of common ground, understanding that language is different, respecting the difference with no dismissal, that is, no power struggles*

between the organisations” while other groups stated the importance of being “respectful of each other’s expectations/point of view”.

Consistent with feedback received through the Forum discussion and highlighted in this summary report WANADA and WAAMH commit to coordinate future Cross Sector Forums.

“The chance for more Forums in future to allow further discussions so collaboration between sectors can continue to evolve and develop”;

*“Similar Forums around what works and what services are being provided across the sectors” including opportunities to “interrogate and examine the difference between the AOD and MH sectors in terms of the delivery of services between the NGO and Government sectors”. Also that future Forums are made more accessible to a wider audience, in particular for “consumers, carers and family members from rural and remote areas” Many groups also requested that a **summary of today’s Forum** be provided not only to those present but that it was made readily accessible to the broader community.*

ACTION: It is proposed that additional Forums are held to progress this commitment, ensuring inclusion of rural and remote input. Information summaries from these forums will be made widely available through a variety of media.

Funding assistance would be required to support progressing these two Forums.

Commitment Statement 2: To reduce stigma and discrimination and enhance service access for people with AOD issues and mental health concerns

Further suggestions included increasing awareness around both AOD and mental health and the services available. The aim of this idea was to reduce stigma and discrimination found in the health professions and the wider community.

“Increased awareness via media to help lessen stigma and discrimination”;

“Make contact with relevant health professional to ensure both sectors are on the same page” including “Co-advertising material at medical centres and General Practice’s”

“Dual representation at events and key meetings”

“More information for families and the broader community including what the issues and impacts of AOD and MH are, how to work with the services that are available and what service constraints there are”; and

“Increase public Forums”, and that these are “held annually so they have an identity in the community and Australia wide”

The MHC commissioned research specific to stigma and discrimination for people with MH concerns in November 2012. Subsequent to this WANADA has commissioned research aimed at identifying the following:

- the types of stigma experienced by people that use alcohol and other drugs (eg self, perceived and actual);
- the nature and type of stigma experienced by workers in relation to their consumers and how this impacts on service access to other services of priority to consumers;
- the stakeholder groups most likely to stigmatise and discriminate against people that use alcohol and other drugs.

ACTION: Cognisant of work already being progressed WANADA and WAAMH commit to work collaboratively on reducing stigma and discrimination and consumer participation strategies to support service access for AOD and MH consumers and the broader community impacted by AOD use and MH concerns.

Commitment Statement 3: To support/address barriers and challenges to the machinery of government

And finally in relation to working collaboratively, groups stressed the importance of the Peaks advocacy role particularly in relation to the upcoming merge of the Drug and Alcohol Office (DAO) and the Mental Health Commission (MHC):

“Ensuring ongoing consultation with consumers, families and significant others as the merge of DAO and MHC takes shape in practice”

“Re-enforce that the merge is an opportunity to focus on outcomes for consumers, families and significant others”

“to enhance an appreciation for regional, rural and remote specific needs in this process”

ACTION: WANADA and WAAMH commit to monitoring the impact of the merge of DAO and MHC to help identify future improvements

3.4.2 System Wide and Cross Sector Consideration

Further consistent priority areas emerged from small group feedback. These are presented as recommendation for key stakeholder consideration:

Workforce Development

A number of groups identified the need for ongoing workforce development across the two sectors

“Cross sector training and workforce development activities that are affordable with consumer and family input into training”.

“Learnings from the Capacity Building Initiative in the AOD sector are applied across the board”.

Another group suggested *“Building wider networks between MH and AOD services, consumers family and significant others”* would support shared learnings. *“Encourage work with and across sectors that reflects MH and AOD as the norm”* and *“this requires both a top-down and bottom-up approach”.*

“Sharing strategies and innovation – in co-production/co-design, demonstrating outcomes and application of evidence based practice”

RECOMMENDATION 1: Consideration is given to approaches to workforce development across the two sectors, to enhance shared learning and knowledge transfer, including engagement with consumers, family and significant others.

Other groups noted the importance of involving all levels of services and including consumers, carers/family and significant others in future service co-production:

“Invite and engage with the Public Mental Health system to be part of this conversation” and “capture what works well within and across the AOD/MH service providers, with consumers, carers and family members”; and

“Practical changes could be implemented including looking at referral options between Government MH and AOD services and NGO AOD and MH services”.

RECOMMENDATION 2: Consideration is given to sharing strategies and innovations – in co-production/co-design, demonstrating outcomes and application of evidence based practice.

Additionally a number of groups made comment about the merge, these included some positive and some negative comments:

“The merge should mean an opportunity for improved outcomes for consumer, carers and family members”

“Not happy with name “Mental Health Commission” for the amalgamation of the combined Government bodies, where is the recognition of the importance of the AOD sector – the Commissioner, the Minister and the Premier need to hear this”; and finally

“further development of the 10 year MH service plan needs to include representation from AOD family/carers and consumers”.

RECOMMENDATION 3: Recognition of importance of both sectors, in the responsible body and planning

Appendix A: Cross Sector Forum Reference Group Terms of Reference

Cross Sector Forum Reference Group Terms of Reference

Objective: To plan and progress a Cross Sector Forum between the Mental Health and Alcohol and Other Drug sectors.

Members: 1 representative from each sector from the following groups:

- Family/Carer
- Consumer
- Service Provider

With further representatives from both WAAMH and WANADA

Family/Carer and consumer representatives will be remunerated for their input

Meetings: Facilitated by WANADA and WAAMH
Meetings will be held as required

Terms of Reference:

1. To provide ideas and planning for the format of a cross sector forum
2. To identify strategies that build equitable and inclusive working relationships and understanding between the alcohol and other drug and the mental health sectors, consumers, carers and families

Roles and Responsibilities:

On occasions items of a confidential and sensitive nature may be discussed during the meetings. All participants of the reference group commit to ensuring confidentiality of these matters is maintained.

Peak Bodies (WAAMH and WANADA):

- Co-chair reference group meetings
- Convene and resource the meetings
- Provide summaries/minutes of the discussions held
- Undertake actions as agreed by the reference group

Reference Group Members:

- Consider and put forward options and ideas to facilitate a successful joint forum
- Consider and put forward options and ideas to progress any forum outcomes

Appendix B: Summary Cross Sector Forum Evaluation

