

Carers' experiences of providing care and support to family members with co-occurring severe mental health and substance use issues ('dual diagnosis'), and their engagement in mental health service delivery.

An exploratory research and mental health service quality assurance project.

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Key Abbreviations

| | |
|---------------|---|
| AMHS | Area Mental Health Service (Clinical) |
| AOD | Alcohol and Other Drugs |
| PDRSS | Psychiatric Disability Rehabilitation and Support Service |
| MH | Mental Health |
| NWAMHS | North West Area Mental Health Service |
| VDDI | Victorian Dual Diagnosis Initiative |
| VMHCN | Victorian Mental Health Carers Network |
| VMIAC | Victorian Mental Illness Awareness Council |

Glossary of Key Terms

| | |
|------------------------------|--|
| Carer | Defined as any person providing care or support to an individual with a mental health and/or substance use issue. Carers may include family members, friends or any other significant persons, with the exception of professionals providing such support as a part of service delivery. |
| Consumer | The term used in this report to describe users of clinical Mental Health treatment and support services. |
| Client | The term used in this report to describe users of psychiatric disability and rehabilitation and support services (PDRSS). |
| Clinician | The term used in this report to describe AMHS treatment and support staff. |
| Dual Diagnosis | The term used in this report to describe co-occurring or co-morbid mental health and substance use issues and disorders. |
| Severe Mental Illness | The term used in this report to describe low prevalence mental health disorders associated with significant levels of disability (i.e. psychotic disorders) commonly treated by specialist MH services. |
| Substance Use | The term used in this report to describe the harmful and problematic use of alcohol and other drugs, which may include substance abuse, misuse, dependence and addiction. |
| Support Worker | The term used in this report to describe client support workers employed by PDRS services, which may include Key Workers and Personal Helpers and Mentors. |

Key Implications for Decision Makers

1. The fragmentation of the MH and AOD service sectors places added burden upon carers seeking treatment and support services for family members and significant others with co-occurring severe mental health and substance use issues ('dual diagnosis'). In the absence of robust cross-sector service collaboration, greater responsibility can fall upon carers to advocate for their family members, to integrate and co-ordinate services across sectors, and to provide continuous care and support in the context of marginal service delivery. It is critical that MH and AOD services work in partnership to support both consumers *and carers* at the point of initial service entry (*from whichever service they first present*), consistent with the '*No Wrong Door*'ⁱ approach.
2. Carers regularly fulfill a multitude of key support and protective functions which significantly contribute to the improved safety, wellbeing and recovery of individuals affected by a dual diagnosis. It is integral that MH and AOD services recognise the particularly complex caring role assumed by carers in the context of dual diagnosis, acknowledge that carers are often *doing the best they can with the knowledge, resources and skills available to them*, and routinely assess and identify carer support needs in the context of consumer-focused service planning and delivery.
3. It is important that MH and AOD services engage in *routine family-inclusive, consumer-focused* practice in recognition of the key supportive functions assumed by carers and the role that strengthened family systems can play in consumer treatment and recovery. To improve the capacity and ability of MH and AOD service staff to engage with carers and families, training in family-inclusive, evidence-based practice methods (*such as Single Session Family Consultations and Behavioural Family Therapy*) and the allocation of specific EFT must be a service priority.
4. Given the complexity associated with dual diagnosis, it is integral that carers receive *integrated, targeted and comprehensive* support from MH and AOD to services to strengthen their caring capacities and family relationships, and to reduce the potential for stress and burden. Carers need particular support to:
 - Better understand the correlations between MH and AOD symptoms and behaviours
 - Develop strengthened and more effective communication, coping, problem solving and risk management strategies
 - Implement limits and boundaries that are sensitive to their own values, beliefs, strengths, fears, culture and caring circumstances
 - Address their own needs for safety and self-care
5. The importance and value of carer and family inclusive practice is identified in a multitude of MH and AOD policies, and widely acknowledged in the contemporary literature. The current ***Dual Diagnosis: Key directions and priorities for service development***² document identifies the involvement of carers in service '*advisory and planning activities*' and '*the education and training of staff*' as key service deliverables for all MH and AOD services across Victoria. In response to these service deliverables, it is incumbent upon the VDDI in collaboration with specialist Dual Diagnosis services and MH and AOD services, to investigate and provide *systematic and meaningful* opportunities for the experiences of carers to inform current and future priorities for dual diagnosis service delivery and quality improvement in Victoria.

ⁱ For more information refer to 'The No Wrong Door' website, <http://www.nowrongdoor.org.au/home.html>.

Executive Summary

Context

The importance of engaging carers and family members in the delivery of MH and AOD services is well established across MH and AOD literature and policy. Working with families and carers can not only support improved treatment and recovery outcomes for individuals with complex mental health and/or substance use issues, but can provide an opportunity for services to address carers' own needs for support. Co-occurring mental health and substance use issues ('dual diagnosis') have been long associated with treatment complexity and poorer treatment outcomes, inconsistent use of services and a wide array of associated social impacts such as increased risk of homelessness, poverty, forensic involvement, wider health problems and social disadvantage. Whilst the role that carers and families can play in mitigating adverse outcomes for service users experiencing either mental health or substance use issues is widely acknowledged by services and policy-makers, less is known about carers' *specific* experiences, roles and support needs in the context of dual diagnosis. The present research provides a platform for carers to discuss their experiences of dual diagnosis, and for such experiences to inform the delivery of dual diagnosis treatment and support across MH and AOD services in Victoria. Such an aim is consistent with the objectives identified in Outcome 5 of the Victorian ***Dual Diagnosis: Key directions and priorities for service delivery***² document.

Sample and methods

In-depth qualitative interviews were conducted with 12 carers recruited from three MH services in metropolitan Melbourne. Carers were mainly female, and most provided care to a male consumer with co-occurring severe mental illness and substance use issues. Follow-up discussion groups were held with staff from two participating MH services, enabling staff to respond to, and reflect upon a selection of carer interview themes, and to inform the development of the project's final recommendations. Whilst the number of carers and services involved in the project was relatively small, the project's use of qualitative methods generated rich interview data and provide a meaningful opportunity for carers' experiences to contribute to the wider dialogue surrounding the priorities for dual diagnosis service delivery in Victoria.

Carer interview findings

The carer interview findings were analysed according to themes, and include the following key learnings:

- Carers provide critical advocacy and support to family members with dual diagnosis in a fractured MH and AOD service system, and assume a significant role 'making connections' between different services.
- Carers play an important role in the mitigation of risk to family member safety. Carers place boundaries around, and implement consequences in response to family members' substance use behaviours, and respond to immediate acts of harm (i.e. overdoses). The implementation of boundaries is a complex process for carers, many fearful that the withdrawal of support may result in significant risk to family member safety.
- Carers provide a safe place for family members to live, often when no other safe, suitable or supported accommodation options are available in the community.
- Carers provide financial and material support to family members, and are often significantly affected by acts of theft undertaken by family members to support substance use.

- Carers support family members' development of independent living skills and engagement in training and study, and are significant sources of companionship, hope, and acceptance.
- Carers regularly experience compromised personal safety, evidenced through threats, abuse, violence and exposure to family members' risk taking and criminal behaviours and activities. The emotional and psychological impacts that result from providing such complex care are various, and can include despair, fear, anxiety, anger, trauma, helplessness and depression.
- Carers often experience strained family and spousal relationships (e.g. when different points of view are held between partners), together with feelings of isolation, judgement and blame from friends, family and services for their perceived role in the maintenance of family members' complex dual diagnosis symptoms and behaviours.
- Improved access to complex and integrated information about dual diagnosis was a high priority for carers, together with ongoing support to make sense of, and apply such information to their own caring circumstances, values and beliefs.
- Family-focused psycho-education and information forums on substance use and/or dual diagnosis were found to be useful, particularly in the early stages of diagnosis. Courses were most useful when they included information about *ways to best respond to, and support their family member with a dual diagnosis* (e.g. problem solving strategies, how/if to set limits, communication strategies) together with more general information about the symptoms, behaviours and correlations associated with different mental health conditions and substances.
- Carers felt that MH and AOD services often underestimated the complexity associated with co-occurring *severe mental health and substance use disorders*, and the effects that withdrawing carer support could have on a vulnerable family member's wellbeing, safety and functioning.
- Carers reported the need for greater collaboration, partnership and engagement with MH and AOD services, and more comprehensive cross-sector integration of the MH and AOD service sectors.

Staff discussion group findings

- There was wide acknowledgement of the protective roles assumed by carers.
- Resources and lack of training in family-inclusive practice methods (such as family meetings) were seen as a hindrance to wider and more meaningful carer engagement by MH staff.
- Staff demonstrated strong support for family-focused psycho-education programs was, particularly their focus on improved family communication, problem solving and collaborative treatment planning.
- Early engagement with carers seen as critical by some staff.
- Staff acknowledged that the caring role in the context of dual diagnosis is complex, and that there is a need for services to respect the decisions made by carers and reserve blame.
- Some concern was expressed by PDRSS staff regarding the potential for family engagement to undermine the sector's consumer-empowerment and recovery focus. Further concern that one-on-one engagement of carers is not a funded service activity in the sector.

Implications and recommendations

Ten recommendations are presented in the report, comprising strategies for strengthened carer engagement with MH and AOD services, and improved collaboration and integration between the MH and AOD service sectors.

The key strategies underlying each recommendation are detailed in [Section 4 of the main report](#). The strategies focus on the ways in which MH and AOD services can foster *early, routine and meaningful* engagement with carers and families whilst maintaining a consumer focus. Such engagement includes the ways in which services can:

- Support carers at the point of initial contact, intake, referral and service entry across MH and AOD services
- Better identify and address the support needs of carers via routine early engagement and the regular use of family meetings and consultations
- Support strengthened family functioning and resilience in the context of significant complexity
- Support carers to access integrated and targeted dual diagnosis information
- Support carers to more effectively respond to, and cope with complex behaviours and circumstances, in the form of improved communication, coping, problem solving and risk management strategies, and support to implement limits and boundaries that are sensitive to their own values, beliefs, strengths, fears, culture and caring circumstances
- Acknowledge the impacts of dual diagnosis on carer safety, security, health and wellbeing.

The key strategies also identify the need for:

- Strengthened and more systematic training and support for MH and AOD staff to engage in routine family-inclusive practice
- Strengthened focus on family-inclusive practice in the PDRSS context of consumer-recovery
- Strengthened systemic opportunities for carer experiences to inform the quality improvement processes of MH and AOD services in the context of dual diagnosis (consistent with Outcome 5 of the *Dual Diagnosis: Key Directions*² document)
- Greater access to supported housing for consumers; to support improved consumer independence and recovery and reduced carer burden.

The importance of strengthened collaboration between MH and AOD services is a final over-arching key recommendation of the report, reflecting many of the recurring concerns expressed by carers regarding the MH and AOD sector's lack of systematic integration, cohesion and collaboration.

1.0 Introduction

Literature and policy review

The complexities associated with co-occurring mental health and substance use issues and disorders ('dual diagnosis') are acknowledged across MH and AOD policy and research. Dual diagnosis is widely associated with poorer treatment and recovery outcomes, greater service complexity and service utilisation, chronic illness development and heightened risks of homelessness, poor physical health, social disadvantage, criminality and incarceration and exclusion from services (i.e. 'falling between the gaps' of service systems)⁽³⁻⁷⁾. The notion that dual diagnosis is the '*expectation rather than the exception*' for individuals with either a mental health or substance use disorder is now widely accepted, and has informed the development of strengthened dual diagnosis service priorities over the last ten years in Victoria and across the Commonwealth; evidenced through the Victorian Dual Diagnosis Initiative⁸ and the National Comorbidity Project⁹.

Consistent with the complexities associated with dual diagnosis for consumers, the caring burden assumed by carers can be likewise challenging and difficult, particularly in the context of poor MH and AOD service integration. Anecdotal evidence suggests that such service system fragmentation can place added pressure on families to become the '*care providers of last resort*'¹⁶, particularly when family members with dual diagnosis have become disengaged or marginalised from formal support services.

The potential impacts of family member mental illness and/or substance use on carers and families are well documented, as are carers' self-identified support needs. Such impacts include high levels of reported stress and burden, financial hardship, compromised psychological, emotional and physical health, family conflict and risks to carer safety⁽⁹⁻¹²⁾. Frequently identified carer support needs include the desire for *ongoing, accessible and non-judgemental* engagement with treatment and support services, and improved access to information, emotional and psychological support, respite and financial assistance⁽⁹⁻¹⁵⁾.

The value of working collaboratively with family and carers in the delivery of mental health and AOD services has been long associated with strengthened outcomes for consumers, carers and families alike. Such outcomes include the potential for:

- Improved consumer treatment and recovery, including reduced rates of relapse, fewer and shorter periods of hospitalisation and improved consumer engagement with services⁽¹⁵⁻²⁰⁾
- Improved consumer stability and safety⁽¹⁵⁻¹⁶⁾
- Reduced consumer poverty, homelessness and social exclusion¹⁶
- Strengthened family functioning and adaptive communication, and reduced family conflict^(14-15, 21-23)
- Decreased levels of reported carer stress, burden and exposure to risk and violence^(14-16, 18, 20-22)
- Improved access to carer support, and strengthened carer resources^(14-15, 18, 20-21)
- Improved limit setting by carers, and reductions in carer/family behaviours that may unintentionally support continued consumer substance use behaviours^(15, 21-22)

Support for carer and family inclusive practice can be found in a range of contemporary MH and AOD policies, plans and service guidelines in both Victoria and across the Commonwealth. These include the **National Standards for Mental Health Services**²³, the Commonwealth **Consumer and Carer Participation Policy**²⁴, the Victorian **Caring Together Action Plan**²⁵, the Victorian **Mental Health Reform Strategy 2009-19, Because Mental Health Matters**²⁶, the Victorian **A New Blueprint for Alcohol and Other Drug Treatment Services 2009-2013**²⁷, and the **National Drug Strategy 2010-2013**²⁸. Such policies recognise the role family and carer engagement can play in strengthened service outcomes, and emphasise service cultures that see '*consumers,*

carers and families as valued partners in treatment and care, and in service governance, planning and evaluation²⁶.

The importance of carer and family collaboration also extends to contemporary dual diagnosis policy, in particular the Victorian ***Dual Diagnosis: Key directions for service priority development***² document. In service delivery Outcome 5, two specific consumer and carer related Key Performance Indicators are outlined. These require MH and AOD services to (i) ‘develop mechanisms and processes that enable consumer and carer input into advisory and planning activities’ and (ii) enable ‘consumer and carer involvement in education and training of staff’. Together with these specific objectives, the document also captures a carer’s experience in a more personal manner in the form of one family’s individual story of dual diagnosis. This story not only highlights the importance of dual diagnosis ‘capable’ service provision across MH and AOD services, but also the roles that carers and families members can play in consumer care, and the value of family collaboration in the delivery of consumer-focused treatment and support.

Project aims

The project aims to explore carers’ experiences of providing care and support to consumers with mental health and substance use issues and disorders (‘dual diagnosis’), and their experiences of collaboration and engagement with mental health services. The project also aims to capture the views of MH service staff regarding their engagement with carers in the context of dual diagnosis issues. The project seeks to identify specific carer support needs relating to dual diagnosis care, and factors supporting or impeding carer engagement and participation in services. Consistent with the key performance indicators outlined in Outcome 5 of the *Dual Diagnosis: Key Directions*² document, the project aims to provide a platform for carer experiences to inform the wider delivery of dual diagnosis treatment and support in Victoria, including priorities for MH and AOD staff education and training, service planning and quality improvement.

2. Approach

Recruitment of carer participants

Carer participants were recruited from three publically-funded specialist mental health services across Northern, North-Western and North-Eastern Metropolitan Melbourne. The services comprised one AMHS (the North West Area Mental Health Service) and two PDRS services (Neami and the Mental Illness Fellowship through its ‘*Well Ways Duo*’ programⁱⁱ). These services typically provide treatment and support to persons with low prevalence severe mental health disorders (such as schizophrenia, bi-polar disorder and severe mood disorders) and psychiatric disability. In order to maximize the project’s inclusiveness, a formal diagnosis of dual diagnosis was not a requirement for participation, only a recognised history and pattern of relevant symptoms and behaviors. It was required that carers be users of the service within the last 12 months, and be at least 18 years of age.

Carer participants were recruited from specific programs within each of the participating specialist MH services. The researcher provided information to each service about the project’s aims, purpose and intended methodologies, and provided all the material resources required to aid carer recruitment. As the researcher did

ⁱⁱ The *Well Ways Duo* program is a 6 week, peer-led group education and support program for families and friends of people with co-occurring mental and substance use issues. The program provides information about: substance use behaviours, the symptoms and treatments associated with various mental health conditions, the interaction between mental illnesses and drugs and alcohol, about coping strategies and self care strategies, including how to address and manage risk and violence.

not have consent to make initial contact with carers directly, such contact was undertaken by service representatives on the researcher's behalf. These representatives provided carer candidates with information about the project via an information sheet, and in many cases also provided carers with verbal information about the project. Interested carers were then asked to contact the researcher directly, thus limiting any further direct involvement with the service. *The recruitment processes undertaken at each participating services are detailed in Appendix A.*

Limitations of sample

As sampling was undertaken on a convenience basis by service representatives rather than systematically across all carers associated with a given service, the sample is potentially most representative of carers with some form of prior engagement with the service. The consequent homogeneity in the carer sample characteristics (further discussed in the findings) may be in part attributable to this sampling method. A more diverse carer sample may have also been obtained if sampling had been extended to specialist AOD services that typically engage consumers with lower severity mental health disorders (such as anxiety and depression) and more severe substance abuse disorders. As such, the findings are most representative of the experiences of carers who have had some form of contact with services, in the context of a family member's severe mental health and substance use issues.

Whilst the number of participating carers and MH services was limited to 12 carers and three services respectively, such sample numbers are typical of social research with an exploratory and qualitative focus, and do not necessarily weaken the trustworthiness or potential usefulness of the research findings. It is also important to note that whilst the project's sample size and sample characteristics limit the generalisability of the findings to a broad range of carers and service contexts, the findings nonetheless have broad resonance with the wider body of carer and family literature, in particular with some of the themes identified in the Final Evaluation Report of the Odyssey House 'Family Eclipse Program'²⁰ (a program for young adults and families affected by dual diagnosis). Such parallels are noteworthy for the purpose of service delivery, as they suggest that the experiences, support needs and methods of working effectively with carers and families are fundamentally similar across a range of caring and dual diagnosis contexts.

Carer qualitative interviews

In-depth qualitative interviews were held with 12 carers providing care to a family member with a dual diagnosis. Interviews were of a 90-180 min duration. Interviews were conducted utilising a schedule of semi-structured interview questions designed to guide the interview process (*refer to Appendix B*). The interview schedule was designed to elicit participant accounts of their own experiences of caring, support and the service system, in a rich and detailed fashion in a manner most meaningful to them. All carer interviews were recorded and transcribed with the permission of participants, and each transcript de-identified to ensure consumer, carer and service confidentiality. A thematic analysis of each carer interview was conducted, with a focus on identifying and extracting themes from the interview data

Staff discussion groups

Discussion groups were held with staff from two of the participating mental health services (NWAMH and Neami). The discussion groups provided an opportunity for clinicians and support workers to explore their own experiences of working with carers specific to dual diagnosis, and to respond to three key discussion points drawn from the overall carer interview findings. As per the methodology utilised in the carer interviews, the focus groups were digitally recorded, de-identified and analysed according to themes. The duration of each discussion group was limited to 60 minutes. *Appendix C details the key discussion points presented to staff, and the questions utilised to guide staff discussion.*

3. Findings

Carer qualitative interviews

Sample characteristics

12 carers took part in the qualitative interviews. Three carers were recruited from the NWAMH service, five carers from multiple Neami PDRS services and four carers from MIF's Well Ways Duo Program.

The following table provides an overview of the key characteristics of the carer participant sample.

Table 1.0 Demographic data and key characteristics of carer sample

| Carer | Carer Sex | Carer Age | Caring relationship | Consumer Sex | Consumer Age | Consumer diagnosis | Resides with carer |
|-------|-----------|-----------|---------------------|--------------|----------------------|--|--------------------|
| C01 | F | 50-60 | Mother | M | 20-30 | Schizophrenia, codeine/ cannabis /alcohol use | N |
| C02 | F | 60-70 | Mother | M | 30-40 | Schizophrenia, alcohol/ heroin/ cannabis use | N |
| C03 | F | 50-60 | Mother | M | 20-30 | Schizophrenia, cannabis/ speed/ alcohol use | Y |
| C04 | M | 50-60 | Father | M | 20-30 | Schizophrenia /cannabis/ speed/alcohol use | Y |
| C05 | F | 50-60 | Mother | M | 20-30 | Borderline Personality Disorder, amphetamine /cannabis/alcohol use | Y |
| C06 | F | 50-60 | Mother | M | 20-30 | Schizophrenia, alcohol/ cannabis/amphetamine use | N |
| C07 | F | 50-60 | Mother | M | 30- 40 | Bi-polar Affective Disorder, cannabis/ alcohol/ amphetamine use | N |
| C08 | F | 60-70 | Mother | M | 30-40 | Bi-polar Spectrum Disorder, Alcohol use | Y |
| C09 | F | 50-60 | Mother | M | 20-30 | Schizophrenia, ADHD, cannabis and amphetamine use | N |
| C010 | F | 50-60 | Mother | M | 30-40 | Schizoaffective Disorder cannabis/amphetamine/ alcohol use | Y |
| C011 | F | 40-50 | Sister | M | (Deceased at 50 yrs) | Major depressive disorder, alcoholism (death due to liver failure) | N |
| C012 | F | 50-60 | Mother | M | 30-40 | Schizophrenia, amphetamine/ cannabis/ alcohol use | Y |

Consistent with the population of consumers typically engaged by specialist public mental health services, the majority of participants identified as carers to family members with a severe mental illness and/or psychiatric disability. The majority of participants reported that their family members were users of mental health services, had severe mental health disorders and were poly-drug users. Approximately half indicated that their family members had experienced some contact with an AOD service in the recent past. In terms of cultural

diversity, half of the carers interviewed were born outside of Australia, and a quarter spoke a language other than English.

As detailed in Table 1.0, the majority of carers interviewed were *parents* of a consumer with a dual diagnosis (11 carers), *female* (11 carers) and aged between *50-60 years of age* (9 carers). Whilst such characteristics are typical of carers associated with specialist mental health services, capturing greater sample diversity with regard to gender, age, caring relationship and culture may have lent further breadth to the overall findings. The absence of carers providing care to female consumers is a notable omission from the sample, as is the lack of male carers or young carers (due to ethical constraints it was not possible to engage carers under the age of 18yo). Unfortunately, despite multiple attempts to recruit a broader sample of carers, a more diverse sample could not be obtained within the time constraints of the project.

Carer interview themes

Key themes from the carer interview data are presented below according to four categories: ***the protective role, the supportive role, the impacts on carers and carers' experiences of services.***

The protective role:

A key theme expressed by all carer participants was that of the 'protective role' assumed to support consumer safety and wellbeing, and mitigate the potentially harmful outcomes of risk taking behaviours. Whilst this protective role was experienced as multifold, complex and variable between carers, participants were unanimous in their belief that the support they provided during their family member's illness, treatment and recovery pathway (particularly in the absence of service engagement) had been *critical in minimising harm and keeping their family members safe and alive*. Carers 5 explains:

Well, I had to do it. I had to do it, I've had to save him. I had to save him from himself too, because had I not taken the course that I had and I hadn't of been there sitting with him and pleading with him he'd be gone, I was the only one he would have listened to.

Carer 5

For the carers interviewed, this protective role extended to the following key functions:

a. Response to critical incidents and risk taking behaviours

All carers described times when they had intervened to protect their family members from serious harm. Carers described responding to substance use overdoses within and outside of the family home, physically restraining their family members from driving vehicles when substance affected, paying family members' debts when they were under threat of physical harm, impeding family members' attempts at self-harm and calling crisis services (i.e. police, CATT etc) when their family members were at risk to themselves or others

...he's all black and blue and there's water seeping from his ear, he's black, he's gone, he's just got his jocks on and the needles next to him and he's sideways on my bed. What I'm saying is if we got here an hour later, because it took them 25 minutes to get him back, they took him into hospital and they couldn't get him, an hour later and he would have been dead...

Carer 10

He had a pair of scissors that he had sharpened to razor sharp and another occasion when he was drunk, he was high, and he was extremely depressed and he had them to his throat. / He turned around like that and I grabbed them and I threw them right across the front lawn. / He wouldn't have hurt me,

but he would have hurt himself and I had to do something fast. All the knives in the house were all hidden. They've been hidden for four years.

Carer 5

b. Support and advocacy to assist loved to access and effectively utilise services.

Carer participants spoke of the important role they assumed advocating for their family members; helping them to access and navigate a range of service systems, and to receive appropriate and equitable treatment without 'falling between the gaps' of the MH and AOD service systems.

And he came home one day after he'd been out drinking that night and he said to me, Mum, I really, really need help and I can't remember and I spent two days solid on the phone with every contact I knew trying to get help for him. Nobody was interested. ... It was like, sorry, he's too old, sorry, we only deal with drug and alcohol addiction or, sorry, we can't do anything because of his mental state unless he comes in. I said but he's asking for help. No, sorry. I even rang (a drug detoxification service) and had a chat with them and they said but he doesn't need detox because he was detoxing himself because he'd go out on the weekend and then he'd stay clean. ... I spent two days trying to get my son help, nothing, couldn't get anything.

Carer 2

Carers spoke of advocating for their family members across a range of settings (in-patient, community mental health, PDRSS, community support services, the legal system etc), and of the frequent need to be assertive with staff to support their family member's access to appropriate and equitable treatment. The carer advocacy role is illustrated tellingly through the experiences shared by Carer 9:

So because we wouldn't accept that they were discharging (my son), because I said he's dual diagnosis, they didn't want to know it. They just treated him as (a drug user), because (my son) had admitted that he'd used Ice a few days before, so they just treated him, just get rid of him. I mean and it was blatantly obvious that they did not want to deal with him, once he mentioned he'd used Ice, they did not want him in that hospital. And so then, they called security. We weren't yelling or anything like that, but we were demanding that he be treated, that he be seen, because when (my son) goes "Oh my God, I've done something. I'm out of it. I'm out of control. I need help" and there's usually the phone calls, you know, "Please help me mum". He doesn't know what to do but he's realising himself that everything's out of control. Then I know he needs help.

Carer 9

Similarly, Carer 2 argued that her provision of ongoing advocacy for her son had been critical to ensuring that he received appropriate mental health treatment following years of marginalisation from services. She describes the following:

When he committed that armed robbery I contacted the CAT team. I rang the CAT team and I said I need to speak to somebody. I said my son's ill, I know he's ill. A few days later they admitted him to hospital, a lot of work on my part.

Carer 2

Together with assisting family members to access and navigate service systems, carer participants fulfilled the following specific support functions:

- Assisting family members to attend multiple appointments (e.g. transport).
- Attending, and contributing to treatment sessions
- Providing collateral information to mental health professionals and services

- Encouragement to follow through with treatment, recovery plans and goals in the home (e.g. use of services, appropriate use of medication, participation in activities).
- Active participation in treatment and recovery activities
- Advocacy for their family members in the criminal justice system

These support functions are captured accordingly:

...because he lost his license through a car accident and drink driving, I tend to take him to medical appointments to ensure he goes and encourage him to go.

Carer 6

At one stage we were having six and seven appointments every week (with services across different sectors)... and he wouldn't go to any of them on his own.... He was using his and my life.... I was just on call all the time, all the time. Yes, we had psychiatrist, a case manager, a drug and alcohol counsellor, psychologist, (PDRSS) support worker and his normal GP, that's six different people.

Carer 5

I went to most of the meetings with (my son) and I said to him "(my son), do you want me to go in with you. You go in first and then can I come in?". Sometimes I've listened to what he's said and I've corrected him because different reasons that he wouldn't have said something. Sometimes he was too embarrassed to say something and I would have to remind him "(my son), it's in your interest to be honest". So I feel in some of those circumstances he wouldn't have been treated as well as he has.

Carer 10

He couldn't concentrate because the medication he was on was very extreme and so I kept the mood diary (for him). His psychiatrist said I don't want you to keep it; I want him to keep it. I said you either want it or you don't want it, because if he's not going to write it, you're going to have nothing. From the mood diary that I kept for him, they realised he wasn't getting any highs, it was all depression and he was extremely suicidal. So they realised that he had BPD...

Carer 5

I tapped the barrister and I said, no, it wasn't then, it was then and (the magistrate) looked over at me and she said are you (the consumer's) mum? and I said yes. She said could you throw some light on what happened in this space of four weeks when he picked all these fines up and I said yeah. I said 'we didn't know it at the time, but we can now tell you now he had a psychotic episode'

Carer 2

Some carers also assumed systemic advocacy roles in the mental health system; e.g. through participation in Carer Advisory Groups, engagement in formal education and training, and (as detailed by Carer 4 below) and pursuit of vocational opportunities in the mental health services:

Having the problem, dealing with it, the behaviour, the ups and downs of drug taking, they become violent, they become aggressive and you need to develop some sense of how you're going to cope with it, so I decided to get a job in mental health services, so I got three jobs in mental health services. I got a job as a carer consultant, as a carer advocate and as a consumer consultant in different areas of mental health services.

Carer 4

c. Providing a safe place for their family member to live

Over half of the carer participants co-resided with their family members at the time of interviewing, and many others provided support for their family members to live independently. Carers felt that the support that they provided in this regard was critical to their family member's safety, mental and physical health, social connectedness and financial security. Moreover, by co-residing, carers felt that their family member's access to illicit substances and contact with other substance users was minimised, with available forms of independent housing (such as public housing, rooming or boarding houses and SRSs) seen as unsafe, lacking in support and structure, isolating and inconducive to recovery due to proximity to illicit drug suppliers and other drug users (i.e. immersion within a 'drug culture'). The following reflections illustrate these concerns:

He was not going to come home (from hospital) this time, but there's no place really for him to start off with a flat on his own and you don't want them in hostels or those places out near (X) where there's a lot of druggies anyway, you don't want them in that spot if they're really stressed out and their mate's got something and they've got those people around

Carer 12

...there's a saying among carers that there are two places for the mentally ill here, one is prison and the other one is on the streets and unless families stand by and help, that's what happens. It'll happen to my son over my dead body and the ones that are doing the caring are the ones that turn up to these meetings and you'd be surprised, I've met a number of (carers) with dual diagnosis who are quite penniless.

Carer 2

Many carers felt that the decision to co-residing with a family member was impelled upon them by a lack of alternative housing support available for people with complex needs in the community. Carer 2 explains:

I told (the hospital) that he couldn't come back to live with us. I wasn't having him here and on the day he was due to be released she rang us up and said we're going to put him in a taxi and send him to the homeless shelter and he was in plaster and he had a fractured leg and they were sending him to a homeless shelter. I couldn't believe it and he has to be there before four and I couldn't face that so we went down and picked him up, brought him home again. Thank you, God, we did.

Carer 2

The lack of alternative accommodation for family members in the community was also a key factor motivating some carers to provide financial support for their family members to live in a safe independent manner in the community. Carer 6 explains:

...we are supporting him directly. He tried to get rental accommodation but because he had no money and had very bad experiences in the past, rental places he had shared and been left with the bills and no means of paying them, then there had been major issues, so I didn't think anyone would want to rent to him, he was unemployed, got mental health issues, drug use issues, and doesn't interview well. He's a very bad risk for accommodation, so I ended up using up some of my investments and my property that he could live in two or three blocks away so that I could assist him./....it had to be somewhere where I could visit him and keep an eye on him and encourage him to look after himself better.

Carer 6

Lastly, co-residing with family members was seen by some carers as a way of supporting their family member's development of living skills and engagement in positive activity, as Carer 12 explains:

I just feel if he is in a hostel and had his private room, well, you can just see them, you know, they don't really cook, they don't have that family, they don't do anything, they just sit around with the other blokes going in and out... and probably all those people are bored just sitting around anyway so they're having more drugs.

Carer 12

d. Setting boundaries and implementing consequences

Many carers spoke of the role they assumed discouraging and setting boundaries around their family member's substance use and other risk taking behaviours (particularly within the family home), and of following through with reasonable consequences as a way of encouraging family members to take greater responsibility for their choices and actions. For each carer what constituted a reasonable or acceptable boundary differed, and was informed by a combination of factors; both carer-related (such as their values, beliefs, number of years spent caring, coping levels, access to support and fears) and consumer-related (such as a consumer's access to alternative supports, mental health, levels of drug use, stage of recovery, housing situation, strengths, resilience, vulnerability and level of insight. Carers describe their experiences below:

We were on top of him all the time, threatening him, 'we're going to kick you out of the house, you won't have nowhere to live' and that frightened him so he started to think, well, maybe I should change./ I was saying to him we don't want these people coming all hours of the night, these friends that take drugs. They come in here and they drink and it's not good. We don't want these sort of people here. We want a little bit of dignity. You're not giving us that dignity and we can't help you if you don't help us to help you.

Carer 3

... he's staying in some pretty yucky places, but part of that too was sort of like, Well, you want to go down this path, they're the places you're going to live. /We've stepped back forcing him to take steps forward.

Carer 9

Yes, I've told him "I do not have (alcohol) in the house (my son)" and I don't know whether I'm doing right or wrong but I feel it's our house, we don't drink and it does him no good and for a long time now I haven't found any bottles.

Carer 8

e. Financial and material support

A consistent theme across all carer interviews was the financial and material support provided by carers, and the difficulty experienced by many consumers to manage their money effectively. Providing (usually limited) financial assistance was seen as a means of supporting a family member's safety and stability, and of mitigating the risks associated with poverty and homelessness. For Carer 5, the financial impacts of the support provided to her son were particularly devastating:

(I'm) too far gone. I'm surviving day by day. I will never recover from that. / Because no matter how long I live I'm never going to be out of debt. / And the ones, the ones who have helped me won't live long enough for me to pay them back. Sorry. I can handle everything else and I will handle this. So

long as he can get rid of this addiction, if it goes on any longer there's nowhere else for me to go, there's nothing left. I can't borrow any more.

Carer 5

Whilst most carers considered it important to limit the amount of money provided to their family members (as a way of discouraging substance use and encouraging a family member's responsibility for self and development of independent living skills), most carers still assisted their family members with the payment of some bills, medication, food, clothing and other debts when needed. Carers 8 and 6 describe the following experiences:

Yes, we've had to help him financially but he's been told there's no more financial help. Only with his tablets or anything like that, anything to do with his problem, I don't say to him or "If you can't pay your doctors bill I'll pay it" but if the need should come up, we will help him there. But we wouldn't help him out financially in other ways.

Carer 8

I try hard not to give him any money because it will be spent on the wrong things, but to buy him some food or invite him up for meals. But I frequently have paid telephone and gas and electricity. He's supposed to pay me some rent but generally doesn't. (We) (h)ad some big debts to pay off (for him).

Carer 6

The financial support role provided by carers also extended to the provision of financial management, guidance and representation (e.g. financial administrators). Many carers spoke of their family member's lack of financial understanding and management skills, and indicated that the development of such skills needed to be a greater focus in service delivery (i.e. particularly in the PDRSS sector) as a way of supporting consumer independence, and reducing the likelihood of financial harm, hardship, vulnerability and the associated impacts of homelessness.

'He's got a problem. If he's got a dollar, he'll spend it, so I had to become his administrator.

Carer 3

... I'd like somebody that could talk to (my son) about finances and getting his life right, about even living at home. He has to accept that there are rules at home, like with the drinking and that. I don't know that anything like that happens in his life. Instead of me always saying to him "(my son), do this, I think you should do that, you've got bills to pay". If he could go somewhere where they discuss in a group that if you know you've got bills coming up you should do this with your money. I often think I wish someone else would tell (my son) this instead of it being me all the time.

Carer 8

In addition to providing financial and material support to family members, many carers were affected by acts of theft undertaken by their family members to support or finance substance use. For Carer 10, periods of heavy substance use would often result in her son stealing and selling items from the family home, including the carer's clothes and the personal items belonging to his younger sister. These thefts led to considerable financial debt and stress for the carer, family turmoil, sibling relationship breakdown, feelings of insecurity in the family home and distrust in her son.

Finally, many carers indicated that the demands of caring impeded their ability to engage in adequate paid employment. Carers indicated that the financial support they received from the Government (i.e. via the Carers Payment/Allowance) did not provide suitable compensation for this lost income, and that their access to alternative sources of financial support was unreliable and ad hoc. For Carer 3, the distribution of funding

support to carers did not seem equitable or transparent, with some carers perceived to receive more funding than others because their needs were potentially more 'visible' to services:

I think (the funding) should be spread evenly. Yes, because if I'm strong, I'm not accessing the funding or the resources that they have. I'm not asking for much. But my share of what the government gives out to carers is very little to what is used by someone else, and then when I asked for something one time I was told it's not justifiable because the funds have already been used up by someone else.

Carer 3

The supportive role

a. Emotional support, and the provision of hope, love and acceptance.

Carers considered the emotional support provided to their family members as a critical part of their caring role; informing, shaping and strengthening all other support functions. Emotional support entailed listening to their family members feelings and experiences, showing empathy and understanding, being accepting, reserving judgement, communicating hope, providing validation and communicating a belief in their family member's 'intrinsic goodness' and 'worthiness as a human beings'. This latter point resonated particularly strongly across all the carer interviews, with even the most stressful caring relationships seemingly buoyed by a carer's ability to cherish and keep hold of their family member's strengths, goodness and humanity. Given the challenges and hardships posed by all of the carers' dual diagnosis experiences, being able to focus on the 'positive' seemed to bolster a carer's ultimate strength, resolve and resilience, and acted as an invaluable source of hope and acceptance for their family members through their illness and recovery .

(My husband says) "he's never going to do this, and he's never going to do that," as if don't bother. Whereas I don't take that attitude, I'm more hopeful and my feeling is he may improve enough to be doing things even if it's on a part time basis or something. Hopefully he might get a job and be able to look after himself better. I'm a bit more positive, so I like case managers who try to instill that.

Carer 6

...many times he's turned to me, and say after something has gone wrong, do you still love me after this mum? He's got to know that it's there constantly, no matter which way he turned, that it was there for him, the support is there. If they don't have that it's like having no anchor on a ship. As long as that anchor is there they can pull themselves back up, but if there's nothing and they feel like they're a burden to you, they are going to give up and suicide to give you relief.

Carer 5

I think in the end I felt like I was his backbone...

Carer 11

b. Support to develop independent living skills, and engage in training or work-related activity

All carers provided their family members with support to develop improved independent living skills, and to engage in productive or rewarding activity (such as work and training). For carers, independent living skills were considered wide ranging and included: shopping and cooking, managing and attending appointments, and responsibility for financial management. As Carer 8 explains below, encouraging the development of such skills was considered particularly critical for their family members' future once carer support was no longer available.

(My son) says "Ah you're too bossy. You're trying to take over" and I said "I'm not trying to take over, I'm trying to make you understand there's responsibilities in life and that's what he's got to understand.

There are responsibilities. I said "We're not going to be there forever". We're in our 70s and who knows, once you're getting older no one knows how much time they've got.

Carer 8

Carers felt that having something engaging, productive or rewarding to do could enhance their family member's ability to manage or curtail their substance use. For example, Carer 12 utilised her son's goal to participate in the workforce as a means of challenging some of his entrenched substance use behaviours and beliefs:

When you're out there at work, I said, you won't be having a little smoke in the morning, will you? I tried to - I said, if you're going to have it, you ought to keep it till you come home and relax while I'm getting your dinner, you know, kind of - I said you won't be having it (at work) ok?. He says, well, if I'm just doing work on the (factory) floor or something on the line then yes I will...I said you can't work and smoke, you need to concentrate and it's not safe, you'll lose your job...

Carer 12

For Carer 4 the opportunity to be productive and make a contribution was considered 'a basic human right', and that it was incumbent upon services to provide consumers with meaningful avenues to achieve such goals. Carer 4 explains:

So I'm trying to apply myself, but apply myself in not only self help but also trying to help (my son) to actually develop the skills whereby he will be able to develop a greater network of friends, will be able to develop his skills, whatever skills he has and have the opportunity to participate in vocational skills so that unless you have an economic base you will never be able to live independently. You always are welfare dependent and you will never be able to flourish, whatever skills you have or you might acquire to the best of your ability to become an independent person even though you need to live with illness or the symptoms of the illness or medication, but at the same time you will develop your own personal skills to be independent and in so doing you know that you're not just an ill person. You are a person, yes, the illness is part of you but is not all of you so what will benefit me the best would be for me to be of some use to him so that we could develop and access services to develop his abilities in a better way and that would help me. That would help me.

Carer 4

c. Companionship

Most carers indicated that a significant part of their caring role involved the provision of companionship and friendship to their family member; extending to day-to-day companionship in the home and supporting family members to engage in independent tasks. Carers 3 describes the following:

I spend a lot of time with my son. I'm like his shadow. He's with me, I'm with him... We go to the shopping centre together, we go shopping together. If he needs to buy clothes, I go with him. Yes, I'm a lot of his social - I spend a lot of social time with him.

Carer 3

The impacts on carers

For many carers, fulfilling these protective and supportive functions was associated with significant personal costs and sacrifices. These included impacts upon physical health, emotional distress, burn-out, fear and anxiety, trauma, family and relationship breakdown, risk to personal safety, financial hardship, and a sense of putting one's 'life on hold' in order to provide high levels of support. Carer 8 describes such experiences accordingly:

I think I won't give him that chance to get into the drink again. He may not this time but we've thought that before. I've said to (my elder son) "I can't work it out why just during that one weekend when we go away things seem to fall apart for him", and I'm still not sure. I try to avoid giving him the opportunity to get drinking, and that does interfere with our life.

Carer 8

a. Impact on carer safety

Carers frequently described instances in which theirs and their wider family's safety were compromised due to their family members' actions and behaviours. Carers described experiences of abuse and violence, and of being exposed to indirect risk due to their family member's association with criminal activity. The impacts of such indirect risks are captured tellingly by Carers 9 and 5 below:

We had somebody there last week who sat in the driveway and demanded either that (my son) gave him \$400 or something to the value of that. Now, when you say to the value it means something that he can sell that will fetch \$400, and that maybe something worth \$2000 that they will only pay \$400 for. /Either that or I'll smash your jaw, or I'll take your stuff. So I had to go and I went out to him and told him to get lost, don't come near my house again. But I still have to come up with the money to give him or he would have been back smashing my car up or breaking into the house.

Carer 5

It was because of (my son) that our house was burnt down, that we think that these people thought that there was drugs in the house or whatever.

Carer 9

Further, carers described feeling unsafe in the presence of their family members (often in their own homes), of compromising their own safety to prevent their family members from harming themselves and of calling on the police and emergency services during critical incidents. Carers 3, 9 and 5 capture such experiences accordingly:

I wasn't coping with his bad behaviours. I felt threatened. He had people coming all hours of the night to the house.

Carer 3

We ended up in court and (my son) had to have a restraining order put on him to protect his sister, because he was so over the top she called the police one day and he took off after her, threatening to kill her because she'd called the police.

Carer 5

Yes, so when eventually (my son) left the room I threw on some clothes and threw some stuff in a bag...and I got in the car and I rang my husband and I sort of went "This is what's happened, blah, blah, blah, and I'm staying in a motel. You get your arse down here and get him out of my house".

Carer 9

b. Emotional and psychological impacts on the carer

Many carers had experienced emotional and psychological distress, and in some cases, longer-lasting trauma as a result of their family members' dual diagnosis. Carers frequently expressed feelings of anger, fear, anxiety, pessimism, hopelessness and depression. For Carer 9, the many years supporting her son through his dual diagnosis had had profound effects on her own mental health and had led to diminished coping capacities, captured tellingly below:

And honestly I'm sort of thinking to myself "I could kill him". Like I mean physically, I was so fed up and so angry with him and just sort of thinking "Why?" and you don't really understand where it's all coming from and I could've just stood there and kept beating him and beating him and beating him. And then in the end he picked up every chair - we had a slate floor - every chair around the table and proceeded to smash everything.

Carer 9

Further emotional and psychological impacts are described by other carers accordingly:

We were raided, no warrant, no nothing, by the police. It happened in my house. It was dreadful. We'd had such a bad weekend with him ... And I stepped back to put the phone in just in the little hallway there and as I stepped back into there I looked in here and (the police) were surrounding him. They'd come in that back door with no warrant, no nothing. I didn't know who they were, surrounding him around here. ... I went berserk. I went berserk and at that stage they realised they'd screwed up badly because I hadn't even seen a warrant. ... And (my son) was fast asleep in bed, for God's sake and the way they manhandled him and he was fast asleep. ... And I just turned around to them. I said what is he supposed to have done and when they told me, I went he's not violent, he's a sick man and even that day I said to the police my son is a sick man, I know he is. He has been for years and I said I've tried to get him help, I couldn't get him any help. He wouldn't do anything about it, but I'm telling you now my son is a sick man.

Carer 2

(His talk of suicide) affected me really badly because no parent would like to see their kids go before them ever especially to suicide. And when they're under drugs and that paranoia thing and things that are in their head I don't know that's scary.

Carer 7

I find if my son isn't very well, I can go and see him for a little while, but I can't stay very long, if he's upsetting me too much by behaviour or whatever. So I have to go home then and just do things for myself to buoy up my own energy levels

Carer 6

c. Stress on family and spousal relationships

Whilst for many carers, their relationships with wider family members and partners were important sources of support, for others, fractured or tenuous relationships only exacerbated their experiences of burden, stress, isolation and blame. For many carers having different points of view with regard to how to best support or respond to their family member's dual diagnosis was a particularly significant relationship stressor, proving harmful to even the strongest of family networks, as indicated below:

...it's put a terrific strain on my marriage. There's often conflict at home about me being criticised by my husband or my daughter, or for having done too much for him or this or that, so it comes from every

angle, and it's often wearing and tiring, emotionally tiring. My husband tends to get very angry and to be very negative, which makes it difficult.

Carer 6

There was also times that we would feel threatened and abused and there was times that (my husband) and I were arguing about what we should do and the family situation was breaking up. It wasn't good, but we stuck it out because (my husband) and I are two different minds, very different in thinking

Carer 3

...so by this stage, I suppose, my husband and my relationship is sort of I suppose deteriorating. I mean he's fairly volatile too, like vocally, and (my son's) very vocal too and in your face, but most of our arguments were always around (our son), because what (my husband) thought should be done and what I thought should be done were never ever the same.

Carer 9

Multiple carers also spoke of the wider impacts their family member's dual diagnosis had had on other siblings and family members:

His brother wasn't living with us and has only just going to shift back in on Sunday. So there was myself and my daughter. My daughter has post traumatic stress disorder from all that's happened.

Carer 5

(it) has made life a lot harder for our daughter as well because she's lost her brother's companionship and good will and all those things.

Carer 6

My daughter actually, she is not accepting that there's anything wrong with him, she is only thinking that he is spoilt rotten because there is a difference of five years in between them so she really has a grudge.

Carer 7

d. Isolation, judgement and blame

Feelings of isolation, judgement and blame from family and friends were frequently described by carers, particularly due to the negative perceptions associated with substance. Carers 11 and 3 capture such experiences below:

...during my brother's last two years of life, being in alcohol for so long, the family got to a point they couldn't take it any more and it was virtually just me left. Me, I was virtually the only one really left who really went over to see him and was really there for him. Another sister was there but she said to me that 'only under certain conditions, he's got to dry up' or she won't be there. So it virtually just left me. So it sort of made that very hard.

Carer 11

At the time family and friends don't understand the situation. They put their finger on it and say because when he was younger you let him get away with things, it's bad behaviour, he's just naughty, you let him get away with everything, not a good upbringing because sometimes you went off to work.

Carer 3

And at this point in time, my nerves and my thinking can't cope with blame and a child that's giving us hell. Yes, so we took the whole thing on our shoulders and coped with it, just (my husband) and I, not one other person, we've got a big family, when things go wrong with them it's okay, you go running, they let you know that they're not well and you go running, but with us it was just (my husband) and I and nobody else.

Carer 3

Some carers also spoke of feeling judged by MH and AOD service staff, and criticised for undermining their family member's recovery by sheltering them from the consequences of their substance use behaviours. Carer 6 notes the following:

...the criticism we get from doctors, from everybody, as if it's our fault, all these things. So that's pretty hard to take sometimes. Criticism. Some people aren't critical, but some are, and act like we've done too much for him, and when I discuss that with another carer, they might say, "What's too much? I would do anything for my daughter to help." So we're told we've got to step back when people have drug and alcohol issues.

Carer 6

Carers' experiences of services

a. Information provision and education.

Carers indicated that they had particular difficulty making sense of the interrelationships between their family member's severe mental health and substance use issues. Carers were often unsure as to how best support their family member in particular situations, or how to safely implement boundaries and limits. Given the complexities associated with dual diagnosis, receiving information early in the diagnosis pathway was seen as particularly important by carers. Such concerns are captured by Carers 8, 9 and 3 below:

I suppose what I can't put together; has he got the bipolar at that point or is it just he's wanting to drink? That's what I can't get together. /You can't seem to find out much information. I need more help trying to understand the complaint. Am I doing the right thing? Am I handling him right?

Carer 8

You know (my son says), I need the drugs to sort of get through this, and my intelligence gets that but there's still that 'I know you're dual diagnosis, but there's a line'.

Carer 9

Yes. If (my son) goes out to a club one night for example and he comes back and I'm not too sure, I see his face different, I start saying to myself I won't ask him if he's taken drugs. Has he been taking drugs? His behaviour's not good, what can I do? If I decide what to do at that minute, I'd like to know that there's a service available where I can get information or I can get guidance.

Carer 3

Community-based psycho-education groups and courses aimed at providing carers and families with information about substance use, mental illness and/or dual diagnosis were generally found to be beneficial and useful by carers. Of particular use were those courses that combined more general information about common symptoms, conditions, drugs and behaviours, with information about coping, problem solving and communication strategies. For some carers the MIF 'Well Ways Duo' program was a good example of such a program. In some cases, the information gleaned from such courses would later become an important part of a carer's overall armory; assisting them to better communicate with their family members, respond to complex

situations, implement boundaries and advocate for their family members in the service system. Carer 5 spoke of the benefits of once such AOD program accordingly:

It was a six weeks course that I did... /This booklet has been wonderful because every time that I've needed help, I thought that I needed to look something up, I've got it there and I've been able to go over and over and sometimes if I'd get depressed myself, or head towards becoming depressed, I'd get it out and I'd read it again. The book has information about how to deal with various stages of them turning towards giving up their drug abuse and or alcohol or whatever it is and how to deal with them and how to answer them and how to wait and deal with it at a time; and what you should put up with from them and what you shouldn't put up with.

Carer 5

Carers indicated whilst services such as Well Ways and Family Drug Help were useful sources of information and support, drawing upon multiple services for information could be confusing and contradictory. For example, multiple carers felt that the support and information received from AOD services tended to place great onus on the carer 'stepping back', setting boundaries and encouraging consumer responsibility; strategies that were sometimes perceived as inappropriate or even dangerous by carers given their family members serious mental health issues, lack of insight or diminished cognitive capacity.

Carers indicated that they had generally been responsible for seeking information about dual diagnosis/substance use themselves, with minimal support or guidance from the MH services utilised by their family members. Whilst the carer support groups associated with MH services were generally described as valuable sources of support, the information received from such groups was not in itself perceived as adequate or comprehensive, particularly with regard to that specific to dual diagnosis. Accordingly, carers engaged a variety of family-focused AOD support services to meet these support needs, and in many cases, read widely. Carers 1 and 6 describe their experiences accordingly:

(Substance abuse) is not something (the MH service) is focused on. I've probably found if we've asked about drugs and alcohol it's more "Oh, we're concentrating on the medication for schizophrenia" and it's sort of a bit more up to you to go and found out about that really. We've found things out ourselves a lot for the drug and alcohol.

Carer 1

The (MH) service hasn't really helped us, it's really been outside reading and information sessions that we've been to.

Carer 6

b. Support to implement strengthened communication and problem solving strategies

In addition to the provision of information, carers spoke of the need for greater support to implement communication and problem solving strategies, and appropriate limits and boundaries in the context of their own values, beliefs and culture. In particular, some carers held discrepant views to those of service providers, and in turn sometimes struggled to apply the support strategies offered by staff to their caring circumstances. Carer 11 expressed the following:

I found them a bit tough to be perfectly honest. Telling me, like, even before (my brother) died, whilst he was dying, to be very, you know, to hold back and I couldn't do that. I had to keep caring. I couldn't hold back. They were saying he's got to stay in the alcohol and you know, even if he starts to sort of drown in it, come to terms that he's got that problem and get out himself. But I kept going down and to try to give him a boost, a boost to keep - because I was frightened he'd die.

Carer 11

Many carers felt that fear for their family member's safety and wellbeing sometimes hindered their ability to implement limits and boundaries, and that sensitive and ongoing support from services was required to help them to better negotiate and balance such concerns. For other carers though, MH and AOD services were perceived to underestimate the impact of severe mental illness on their family member's capacity to make safe decisions and avoid risk, and to overestimate their family member's capacity to cope with, or 'learn' from the consequences of their substance use or risk taking behaviours. Such concerns are described by Carers 2, 5 and 6 below:

I know what you're doing is you're propping them up and you're stopping them from hitting rock bottom, I know all that. I learned all that in the course, but there was a stage that I could not go past, and I had to do what Al-Anon taught me, and it had to be what sat right with me and I knew damned well there was something wrong with him and I knew damned well he could not cope out there. He could not cope out in normal life and that's why we let him come back. After he was beaten up, you could see the deterioration in him. I thought we were going to lose him. I really was concerned after that that he was going to kill himself and I thought we're not going to keep him for long.

Carer 2

.... they were saying let them take the consequences for their own problems, and if they end up in jail well then let them get into jail because that might be the discipline that they want, that they needand that might be fine with some people but for other people there would be no way out. / Yes, everyone said don't pay his debts, but if I didn't originally pay his debts, he would have gone into a life of crime. It wasn't just house burglaries, it would have been far more intense than that... he would have ended up in jail over it. His personality would have been gone forever and I would never have got him back, he would never have got himself back.

Carer 5

....they just said don't make (your son) comfortable. Put him out on the street.

Carer 6

A particular support need identified by carers related to how to better communicate with their family members, particularly when family members were perceived to be unwell, threatening or engaging in risk-taking behaviours. Carers indicated that they often struggled to contain their anger, fears and emotions, lacked the confidence and skills to respond effectively to their family member's distress, and were sometimes fearful of making a situation worse or getting their family member's 'offside'. Carers described having particular trouble talking to family members about their substance use, and viewed being able to do so more effectively as a critical support need.

I rang the CAT team because I've got concerns about my son, I think he's taking drugs, but I'm not sure. I don't want to ask him, question him, because if he has we might break out into a fight.

Carer 3

My parents couldn't really talk to him, and I thought that was hard - I think people just found him hard to talk to, you know, to get in there, or no one wanted to take the risk, or knew how to.

Carer 11

Yes, yes because you can put your big mouth into it and end up creating problems for yourself. The biggest thing I learnt was to be quiet and listen and let him vent. Then wait until the mood went down and attempt to do things then because it wasn't at that time that you could do anything to.

Carer 5

c. Participation and collaboration with services

Carers spoke repeatedly of the importance of MH services engaging and collaborating with them around their family members' care, treatment and recovery. Meaningful engagement was perceived to be premised on carers being informed, able to contribute and have their experiences and support needs validated and responded to. As some carers indicated that did not have the time, psychological/emotional resources, motivation or need to engage in more depth family support programs or services (such as structured family therapy), engagement with a family member's clinician or support worker was viewed as particularly critical. Such engagement was seen to encompass more than just consultation but genuine consumer-carer-service provider partnership, as outlined by Carer 4 below:

...it's up to the mental health service and the PDRSS to actually bring the family in and say this is what we would like to develop and develop a wellness and recovery action plan and we as carers are part of that. It's consumer focused, but as well it's carer focused, where we as carers are part of all the planning and evaluation of the process, but at the same time everything needs to be written down and evaluated and it's well known. A lot of people go through a relapse whilst drug and alcohol taking, as well as a mental health illness relapse, so we need to learn in the interlude of recovery, we need to actually be in a position to learn as much as possible as carers on how to foresee a possible relapse, not that we can do much about it if it happens, but how can we develop a sense of how to prevent it, so the person isn't hospitalised time and time again.

Carer 4

Carers reported varying experiences of involvement and participation in service delivery. Many carers indicated that their most positive experiences of engagement and participation with services had been enabled via their use of carer-focused services and forums (such as a carer support groups, contact with carer consultants or participation in carer psycho-education programs such as Well Ways Duo program). Carer support groups were almost always viewed positively; carers describing them as useful forums to obtain information, share experiences, discuss problem solving strategies, maintain hope and receive emotional support. The carer consultants accessed within MH services were similarly described as invaluable sources of support, information and advocacy, and their ways of working with carers seen as positive examples of MH services addressing and responding to carers' support needs.

Yes so I'm quite lucky that I managed to get to that group and that they carried me from that hole that I felt like I'm in some kind of a hole, can't get out. In my recovery I can point to the carers group because that is the only thing we have there is nothing else that can help.

Carer 7

Outside of these carer specific services and forums, participants indicated that their contact with case managers, support workers and clinicians tended to be variable and limited, and was often dependent upon an individual worker or a carer's willingness to advocate, rather than a consistent service-wide approach to working with and supporting carers. Carers indicated that they had experienced particularly little contact, collaboration and engagement with the PDRS services utilised by their family members.

No. (The PDRS service) is not for the carer./ No. They're not for carers, they're for the consumer, the patient./ No, when they come in, they usually speak with (my son) and that's usually an hour and that's it. They interact with him, not involve us.

Carer 3

d. *The need for strengthened dual diagnosis 'capable' service delivery for consumers.*

Carers felt that the MH services utilised by their loved could do more to support their family members to address, minimise and better understand their substance use issues. Carers indicated that the referrals made between MH and AOD services were often poorly facilitated and coordinated, and that greater collaboration between workers across sectors could the mitigate some of the difficulties associated with multiple service use and limited consumer motivation. Carers also cited lack of staff time, expertise and motivation (e.g. viewing substance use issues as secondary in the context of severe mental health problems) as further barriers to more successful dual diagnosis interventions. Carer 1 expressed her concerns accordingly:

But although the mental health people have sort of said that "Oh, it's not good him having the other drugs and all that", no he's never actually gone to (an AOD service) about it and we've been frustrated actually.

Carer 1

For some carers, the lack of specialist dual diagnosis workers and support services (such as CCUs with a dual diagnosis recovery focus) was a particular cause for concern. Due to the complexities associated with the care and treatment of consumers with dual diagnoses, these carers felt that the provision of more dual diagnosis training to MH and AOD staff would only have limited effect, and that greater systemic change was required. In particular, carers spoke of the need for dual diagnosis specific detoxification and rehabilitation services, believing that regular AOD service models lacked the flexibility, expertise and resourcing to meet their family member's complex mental health needs. Carers 4 and 3 expressed the following concerns:

Personally I think that it's two different things, and some specialist workers can and do understand both mental health and drug and alcohol issues, and can separate and understand what is the drug problem they're having and what is the mental health problem they're having, but others can't. That's what you really need to understand so you know where you're coming from because it's a chicken and the egg situation.

Carer 4

He was heavily into drug taking and he was unreasonable so he was assessed by (an AOD service) and then placed into (a detoxification unit) but the staff didn't know much about him. They had their rules. They had their way to run their place. They didn't understand that he on medication cannot function early in the morning, so one particular morning he didn't agree to their rules so what they did was close the door on him, there's no place for you here. They have no understanding of the person's illness. He's got mental illness, he was on drugs, maybe alcohol. He agreed to go there to be helped, but that was no help for him because he felt threatened, he felt pushed out./ Then later he we went to (another AOD rehabilitation service). They live in there. They couldn't help him, because it was just drugs only.

Carer 3

Lastly, some carers indicated that greater support was needed from services to help them more effectively address their family member's substance use, whilst others expressed frustration at the perceived 'leniency' of some services with regard to substance use. Carers 6 and 7 recounted the following experiences:

I did the course, but I didn't really feel I learnt a lot from it. /I really wanted to know how to encourage my son to go to detox or to go to counselling, because he didn't want to do these things, so how do I get him there? How do I encourage him to go?

Carer 6

I wasn't happy one little bit because (the case manager was) so lenient against the drugs and alcohol. I was sort of knocked back like (the drug use has) got nothing to do with that and I said but I think it

does.../(The case manager said) drugs have nothing to do with nothing it's plain he's got bipolar mental illness and that's all there is to it./I was very disappointed that (the MH service) has this sort of 'little bit of this and that is okay' attitude. And no wonder my son thought that's a green light flashing I can do (drugs) it's no problem. I reckon it needs to be someone that will help him to completely realise that (substance use) is no good for his mental health and it's no good even for his physical health.

Carer 7

Staff discussion group findings

Sample

A discussion group was held with staff at two of the participating mental health services. Discussion group one was held with staff of the NWAMH service (n=10, including one senior service representative), and discussion group two at a Neami PDRS service (n=7, including one service manager). Participant responses to three key discussion points are presented. The key discussion points (derived from the carer interview findings) and are listed below:

- 1. Carers assume a significant protective role in the lives of consumers with a dual diagnosis. Examples include reducing risk taking behaviours and mediating their impacts on consumer safety and wellbeing, providing a safe place to live, setting boundaries around substance use in the home, advocating for family members in the legal system and responding to overdoses.*
- 2. Carers have an in-depth and complex understanding of their family member's experience of dual diagnosis (including behaviours, symptoms, impacts on functioning, goals, strengths, coping mechanisms, helps, hindrances etc). Involving carers in service delivery was seen as a way of improving the quality and effectiveness of the treatment and support provided to consumers*
- 3. Carers require information and support from mental health services to develop sensitive and effective problem solving and coping strategies. These are required to respond to situations and behaviours associated with dual diagnosis that are often complex, overwhelming, traumatising and unsafe.*

North West Area Mental Health Service (NWAMHS)

Response to discussion point one:

There was wide group recognition amongst participants that carers fulfilled a positive protective role in the lives of consumers with a dual diagnosis. The lack of appropriate accommodation for consumers was perceived to be a particularly pertinent issue, with participants not only sharing carers' frustrations at the lack of appropriate accommodation for consumers, but agreeing that carers were too often relied upon to fill this gap particularly at critical points in a consumer's illness (such as following discharge from an acute in-patient facility). One staff member expressed particular distress that upon consumer discharge '*often the only safe place for them was crisis accommodation unless the family stepped in, that was the cruel situation*'. Likewise, for another participant, drawing on the support of carers was seen to be a pragmatic service response to limited resources, rather than reflective of an ideal system:

'We got to a point that we were very open in family meetings, saying this is the situation that we're all in, and these are the resources that we've got and the pressures that we're under, and after exploring the options we would see a shift in the carers, and they would jump in and go into protective mode and start weighing up what's out there, be it crisis accommodation or a hostel, and then seeing that shift in the carer, and them saying 'we might as well take him home'. Also sometimes having a bit of respite

through the admission period and having access to case management, and seeing some improvement with the person's mental state, could also help carers feel like they could take on their family member again, and sustain them again'.

This same participant noted however that despite the need for pragmatism, the service nonetheless acknowledged the stress providing continued care placed on carers, and respected their right to say 'no' for the sake of their own health, safety and wellbeing. In such instances, maintaining such boundaries was also associated with potential benefit for some consumers, as indicated below:

'On the flipside we also had a lot of families where they couldn't manage at home anymore and then the patient on the ward would have to realize that (crisis accommodation) was the only thing available and this could actually shake them up'.

In terms of the work currently undertaken by staff with regard to engagement of carers, participants indicated that family meetings were regularly facilitated by clinicians, and that both targeted one-on-one support and referrals to family or AOD-specific services (such as Well Ways) were provided. Such support was seen as an acknowledgement of carers' own support needs, and that such needs were made more complex by dual diagnosis.

Lastly, the importance of respecting the decisions made by carers seemed to particularly resonate for one participant, who indicated that this was one area in which service improvements could be made. With regard to carers choosing to pay consumers' bills for example, this participant cautioned against staff criticising or blaming carers, questioned the tendency of staff to offer simplistic solutions to complex situations, acknowledged that there was never a 'right way' of doing things and felt that carers should be supported to make decisions with which they felt comfortable. Such concerns were expressed accordingly:

It's easy for a clinician sometimes to say that (consumers) need to learn to take responsibility for themselves, but what does that really mean? Is it really just a way for us to manage it better for ourselves in our own minds? I would like to be able to say as a clinician, 'this is what it is' and help empower the carer, or whoever is involved, to make a decision and sit with that, and if it is to pay the bill for the consumer or not to pay, then to say that is fine, rather than put a judgement on that and say they are doing the wrong thing'.

Response to discussion point two:

Whilst participants widely acknowledged the benefits of working collaboratively and inclusively with carers and families (and agreed that working with families was indeed a part of their role), lack of time and resources were seen to be significant barriers limiting such work. In particular, staff cited the amount of paperwork associated with their roles, and expressed frustration that the '*need to fill out multiple forms*' often stood in the way of a clinician's ability to collaborate with carers more meaningfully. One participant indicated that whilst the service '*might be seen to be engaging carers by the Department, whether we are actually doing it authentically to any depth is questionable. Of course we're not lying on the forms, but working with families can become a perfunctory function because we don't have time to do more*'.

For another participant, involving carers was seen to be particularly important when working with consumers with a dual diagnosis, indicating that '*due to the added difficulties around dual diagnosis issues I actually find that if the carers are involved the engagement with the (consumer) is actually much better, and we can intervene much better because (carers) can be supportive of what we're doing as well*'. For this participant, imbedding carer involvement in service delivery was a clear way that the service could enhance the effectiveness and quality of its response to dual diagnosis. Other participants similarly agreed that '*we should respect (carers) as experts*', and recognized that carers could offer useful counter-perspectives and provide

critical information where there would otherwise be gaps (particularly with regard to a consumer's treatment history, illness precipitants and symptoms).

Participants further noted that it was important for workers to take the initiative and foster a culture of carer involvement themselves, particularly in the early stages of service delivery when service relationships were being developed, as indicated by one participant below:

I think it's easier to set up (carer involvement) right from the beginning, by being clear about what you're going to discuss, and why (carers) might get involved, so that when a particular issue comes around you've already laid the groundwork'

Response to discussion point three:

Carers' struggle to assist their family members to address their substance use issues resonated strongly amongst discussion group participants, with one staff member indicating that it was '*frustrating for workers too, knowing that (consumers) can get help, but you can't force them*'. For another participant, pro-active attempts to assist consumers to utilise AOD services were associated with particular frustration, as illustrated below:

We often took people to (AOD services) directly from the ward for their first interview, and did all the phone interviews before that with them, and so we really were as proactive as we could be. It's really just very tricky, there's only so much you can do'.

Whilst lack of consumer consent was cited as a barrier that could limit a clinician's engagement with carers, participants nonetheless indicated it was possible to simultaneously respect consumer confidentiality and provide targeted support to carers as well. One participant indicated that in such instances staff could provide carers with general information, referrals and personal/emotional support, and that in fact it was part of the service's responsibility to do so. Moreover, for this participant maintaining contact with carers in a limited fashion was seen as a way of '*keeping the carer involvement door open*' should consumers wish to involve carers more directly in their care in the future.

The Behavioural Family Therapy (BFT) program offered by the service was seen as further evidence of the service's collaborative work with consumers and carers. For one participant, BFT was not only '*a very good way of bringing everyone together for regular family meetings*' but a structured means of providing families (including consumers) with psycho-education, and of supporting them to develop improved communication and problem solving strategies. One participant spoke of her positive experiences of BFT accordingly:

BFT is quite scripted but it also addresses things like psycho-education about the illness component, but also involves the development of a relapse management plan which sets out really clear points about what to do if 'this, this, or this' happens – like who to contact and what options are available. It also goes through communication and problem solving strategies, so I've had instances where two of the families I've worked with where dual diagnosis was involved, where some of the particular problem solving was around the person's alcohol use and how to manage that and what the options were and how things could be done differently. So it's a good way for some of the things that are really frustrating for families to be discussed in a more contained environment, and it's a good chance for everyone to be heard.

Lastly, participants agreed that despite some of the good work already underway at the service, collaboration with, and engagement of carers could nonetheless be pursued more consistently, meaningfully and regularly, particularly if additional resources were made available. Participants indicated that wider use of BFT within the

service could be particularly useful, as might be the use of motivational interviewing (currently conducted with consumers) with carers and families.

Neami PDRS Service

Response to discussion point one:

Participants largely supported the view that carers assumed a protective role in the lives of consumers with a dual diagnosis. One participant indicated that carers seemed to take on a great sense of responsibility for keeping their family members safe, that carers *often 'felt like failures if things did not work out well'* and that carers' attempts to keep *'drugs out of the house were an uphill battle'*. A further participant added that since *'a worker's ability to go into damage control is really limited'* the responsibility for responding to a consumer's immediate health needs during times of crisis (particularly after hours) regularly fell on carers. The role of accommodation as a protective factor seemed to particularly resonate with the group, with participants agreeing that the lack of safe, suitable or 'drug free' accommodation for consumers in the community put undue pressure on families and carers to step in. One participant indicated that *'parents felt compelled to take the person in even though it was not necessarily their wish to do so, and they'd prefer that the person could live somewhere else, but the 'somewhere else' was not usually pleasant or desirable'*.

Some participants indicated however that whilst assuming a protective role was important when consumers were most unwell, it was important that carers gradually *'step back'* as a consumer's health and wellbeing improved. One participant indicated that carers seemed to experience *'anxiety that something would go wrong'* if they limited their support, and felt that as workers it was important *'to build confidence in families to step back'* so that consumers could begin to take on more responsibility for themselves. For some participants the provision of too much (well-meaning) care and support was likened to an act of unconscious *'sabotage'*, which could potentially undermine a consumer's confidence, self-belief and independence. For these participants, it was considered important that the PDRS service support some consumers to achieve greater independence from carers, particularly when consumer-carer/family relationships were strained or complex.

One participant reflected that it *'was probably easier for workers to maintain that hope for recovery'* than it might be for carers who'd *'witnessed many positive changes in the past'* only for their family members to become unwell again. For this participant, *'a balance between taking from the wisdom of the carer and maintaining positivity for the client'* was required, contending that *'ultimately you can end up not understanding each other very well because your roles are so different'*. Similarly for another participant, the challenge was to *'keep the relationship with the family strong whilst also advocating for the client separate from the family'*.

In terms of their current work with families, participants indicated that they were engaged in training to help them as workers to better assess and respond to the needs of children affected by parental mental illness, that they made referrals to family or carer-focused services, and that the service supported the local carer support group (via the service manager). Participants indicated that in their contact with carers they focused on family/carer strengths, encouraged carers to listen to consumers, and included carers in risk management planning where appropriate. In general terms however, participants indicated that they had little time or capacity to work with carers and families, and were restricted by service-wide funding agreements that did not support one-on-one work with persons other than the primary client. One participant noted that *'we can offer that kind of chat and 'good on you' and encouragement to families but we really can't do much more than that except link them into carer support services'*. Concern that family engagement could potentially undermine a client's ability to direct the nature of his/her own also resonated for some staff, as indicated by one participant below:

It can be really hard to bring in the parents opinion when you're trying to build (a client) up to have their own opinion. When you start letting the mum tell the story it can be a bit like 'she's stuffed up here' and 'it's been like this', and 'you don't know what it's been like', and all that emotional stuff comes out and it can weigh down the strengths-based approach, and the respect and value I'm trying to give to the client to show them they've got the capacity to make their own decisions.

Participants indicated that the service could respond differently to meet carer needs on numerous fronts. These included providing more service options for carers, increasing consumer access to stable and supported accommodation in the community, carrying out more frequent family meetings, and supporting some carers to 'step back' in order to promote consumer recovery and increase consumer independence. With particular regard to the responsibility carers assumed in maintaining consumer safety, one participant noted that the service could have a more direct supportive role through the provision of targeted training:

'there's probably a lot of work we can do around helping carers to adjust some of their expectations around the need to provide that safe space 'always', and giving some of that responsibility back to the person themselves for maintaining their own safety, actually giving some formalized training around that'.

Response to discussion point two:

Participants generally agreed that carers and family members could positively contribute to, and support a client's use of services and recovery process. One participant felt that carers could fulfill a particularly useful role during appointments, having '*noticed on many times that things would have got missed if we hadn't talked about it with the carer*'. Another participant noted that he'd '*had some really positive experiences with families, where group meetings had made the work a lot easier*'. Working with carers and families was seen to require sensitivity and balance, and at all times, permission and support from the client. For one participant, getting this balance wrong could not only undermine a client's trust in the service relationship, but also a client's ability to direct the telling of his/her own experiences. The participant spoke of such concerns accordingly:

The responsibility is with the service to provide an environment where there is trust to be able to talk about things (clients) want to talk about, and in my experience carers can be too quick to disclose what they see as going on, which then subverts a consumer's own independence and ability to direct what information they share '.

A further participant indicated that whilst the information received from carers and other sources could be valuable, a client's decision not to disclose information was in fact meaningful and important, and questioned '*if the person is not ready to disclose something whether it would necessarily be helpful for someone else to do so*'. Negotiating such considerations was seen to be complicated however when a client's cognitive capacity or ability for self-insight was compromised; such circumstances potentially requiring greater collaboration with carers in order to effectively evaluate and respond to risk.

Participants noted that whilst many of the concerns raised or held by carers were ultimately pursued by workers in their contact with clients, '*carers may not get the validation that their concerns have been addressed*'. For one participant, providing this sense of validation for a particular carer had been enabled via regular telephone contact, although in general such regular one-on-one contact with carers was not the norm for the service. This participant indicated that whilst her communication with the carer could be difficult, '*by the end of the relationship you feel a lot more confident about it. I won't try to fix anything I was just letting her vent and have her say which seemed to help*'.

For multiple participants, family meetings were seen as a way that the service could validate, discuss and respond to carer concerns and experiences, in turn fostering improved trust and relationship building between

clients, carers and staff members. Family meetings were seen as a transparent way that the service could better involve carers, and were perceived as preferable to individual contact with carers that had the potential to exclude clients. Some participants indicated that they felt uncomfortable and compromised when carers requested that the information provided to workers during phone conversations be kept private from clients, and saw family meetings as a way of avoiding such situations. One participant particularly indicated that she encouraged clients to speak to their families and carers about their recovery goals, rather than take on the responsibility for such communication herself by speaking to carers independently. This was seen as a way of both empowering and giving responsibility back to the client, and of encouraging improved communication within families. Multiple participants noted that targeted training was needed to engage in family meetings more effectively.

Response to discussion point three:

The carer support group associated with the service (and co-facilitated by the service manager) was viewed as the primary way in which the service responded to carer information and wider support needs. Whilst the group was largely described as a forum for debriefing, mutual sharing and emotional support, the role of targeted information provision was also recognised. One participant noted that *'the type of information (group members) wanted was really diverse, from clinical and non-clinical, but also legal and legislative, and what resources were available to them'*. The service felt that the best way to respond to these identified information and support needs was to develop presentations for the carer support group, and indicated that this process was underway at the service. In addition to the carer support group, participants also indicated that they provided carers with information about external support services and courses (such as the Well Ways groups), but felt that such recommendations and referrals were not frequently pursued by carers. One participant noted that it seemed that some carers *'didn't want the information because it's like putting the finger on them and saying that they might have to change'*.

Many participants indicated that their ability to more directly provide information to carers and assist them to develop carer support strategies was generally limited, and beyond the scope of their current roles. More than one participant indicated that if the service was to address carer information and support needs more widely, staff would need appropriate support to do so, both in the form of resources and specific training in family-inclusive practice methods. Some participants indicated that access to such training could strengthen the ability of workers to routinely assess carer needs, and involve families more directly in the review and development of client safety plans.

One participant reflected however that the provision of training was not a panacea, particularly as dual diagnosis was *'a complex issue and there may not be a correct way of dealing with it'*. Accordingly, this participant felt that there was a need to support carers to have greater confidence in their own choices and decisions, as there was rarely a simple or definitive approach to complex circumstances. For this participant it was important that both carers and workers learn to *'step outside of that responsibility'* of always needing the right answer. Such concerns were expressed accordingly:

Sometimes the information that carers want is really specific, like 'what do I do when...?', and 'am I doing the right thing in this situation?', and because it complicated, I sometimes have to go 'I don't know either'.

4. Implications and Recommendations

Ten recommendations for consideration by Government, MH, AOD and VDDI specialist dual diagnosis services are presented. All recommendations are informed by the carer interview and staff discussion group findings, and acknowledge the current policy and service system contexts. **The first six recommendations contain strategies for strengthened carer engagement, and the remaining four pertain to broader issues of service delivery in the MH and AOD sectors.** Consistent with the carer-related key performance indicators outlined in the *Dual Diagnosis: Key Directions*² document, the recommendations provide a platform for the experiences and voices of carers to inform service quality and planning, and the delivery of training and education of staff in MH and AOD services.

Recommendations 1-6: Strategies for Strengthened Carer Engagement

Recommendation One:

Integrated support for carers at the point of initial contact, intake, referral and service entry across MH and AOD services

The point of initial entry into the MH and AOD service systems represents a time of particular vulnerability and need for support for carers affected by dual diagnosis. When service systems are fractured and uncoordinated, accessing services can become more difficult, time-consuming and ad hoc, and greater responsibility can fall upon carers to ensure that family members *'do not fall between the cracks'* and become marginalised. Moreover, in the absence of formal support services, carers and families can potentially assume considerable levels of care and burden.

Consistent with the philosophies embedded in the 'No Wrong Door'ⁱⁱⁱ Approach, the following key strategies are recommended to better support carers at the point of initial service entry.

- 1.1 That screening for dual diagnosis occurs systematically across MH and AOD services at the point of initial contact and enquiry. That the screening tools utilised recognise the protective roles assumed by carers, respect the value of their knowledge and experiences, and have the capacity to identify carer and family support needs.
- 1.2 That carers are provided with consistent and comprehensive information about the MH and AOD services available in their area. Such information should include service eligibility, service role, contact information and intake procedures.
- 1.3 That the service of 'initial contact' (MH or AOD) assumes a facilitative role to assist carers navigate between, and access appropriate services. In some instances, provision of information about relevant services may be sufficient, whereas in others (e.g. when a consumer's or a carer's needs are more complex) a more *active role* may be required by staff to necessitate and support referrals, and to promote early service integration. Such facilitation may involve information sharing between MH and AOD professionals or collaborative intake and treatment planning processes.
- 1.4 Where consumers do not wish to engage in services (or do not provide consent for carers to be engaged in their care), that services assist carers to access carer/family support services and programs, and provide comprehensive information about services for potential use by the consumer in the future. Carer-focused services may include carer/family member focused psycho-education programs (such as

ⁱⁱⁱ The 'No Wrong Door' approach requires that *'all people with co-occurring disorders are actively and meaningfully assisted to obtain appropriate treatment from within the system by the service to which they present, even if they don't meet that service's criteria for treatment'*¹.

those provided by Family Drug Help and the Mental Illness Fellowship's Well Ways programs) and peer-to-peer carer support groups.

Recommendation Two:

Early and ongoing engagement with carers and families

Carers value the opportunity to engage and collaborate with the service providers directly involved in their family member's treatment and care, but feel that the opportunities for such engagement are generally limited. Lack of resources, time, expertise and confidence in family/carer inclusive practice are particular barriers to more routine and effective utilisation of family-inclusive practice methods across MH and AOD services.

The following key strategies are recommended:

- 2.1 That collaborative relationships with carers are established and facilitated by MH and AOD services *early in service delivery*. Such early engagement can foster a culture of inclusion, reduce carer isolation and confusion, strengthen shared understanding and improved communication, encourage collaborative case planning, assist to establish roles, boundaries and expectations, and assist carers to access required support.
- 2.2 That MH and AOD services engage in *periodic* family meetings using, for example, a single-session family consultation model (which includes the consumer), as a means of providing *consumer-centred and family-inclusive* forums for carers to work in partnership with their family member's treatment and recovery. Given the complex and demanding nature of the work undertaken by MH and AOD services, family meetings based upon a single-session family consultation model represent a meaningful, practical and realistic family engagement option for clinicians and support staff faced with limited resources and expertise in family work practice. Such practice also acknowledges the value of routine *engagement and contact* with MH and AOD services for carers and family members, and that not all carers and families have the time, emotional/psychological resources, need or desire to engage in more specialist family interventions, such as ongoing family therapy^{iv}.
- 2.3 That MH and AOD services *actively* facilitate carers' access to more specialist evidence-based family psycho-education interventions (such as Behavioural Family Therapy) to further meet carers' educational and wider support needs (in consultation with the carer)^v.
- 2.4 That appropriate resources be allocated to enhance the capacity of MH and AOD service staff to work in partnership with carers and families, in the form of training in family-inclusive practice methods, regular supervision and allocated EFT. Training may include that with a general family-inclusive practice focus (such as the Bouverie Centre's 'Family-Inclusive' practice training, and the VMHCN's family work modules), and that with a more targeted focus on specific family interventions skills (such as training in family meetings or single session family consultations). Given the particular interest expressed by staff participants for training in family consultation skills (e.g. skills to more effectively facilitate family meetings), the training currently provided through the Bouverie Centre's 'Lighting Beacons' should be considered for wider implementation across a range of AOD and MH service settings.
- 2.5 In the absence of consumer consent, that carer support needs continue to be assessed and addressed by services. That services provide general information about relevant mental illness/substance use

^{iv}This is supported by Mottaghypour and Bickerton's 'Pyramid of Family Care'¹³, which outlines priorities for family sensitive practice in contemporary MH service settings.

^v Services and programs may include the 'Building Family Skills Together' psycho-education program, Odyssey House's Family Eclipse Program for young people and families affected by dual diagnosis, ACSO's 'Restore' family support program for carers and families affected by dual diagnosis in the context of the criminal justice system, EDAS's range of family-focused services, the Bouverie Centre's range of clinical family therapy services and the multiple family group programs offered by select AMHS.

symptoms and behaviours, provide a forum for carers to share their concerns and feedback, and facilitate referrals to carer support programs and services.

Recommendation Three:

Routine assessment and identification of carer support needs

Carers often assume considerable responsibility for the welfare, safety and wellbeing of their family members with severe mental health and substance use issues, often to the detriment of their own health, safety, financial security and personal relationships.

The following strategies are recommended:

- 3.1 That MH and AOD services assess and identify carer support needs *early* in service delivery in conjunction with consumer service planning. That carer support needs are continually reviewed through ongoing service delivery.
- 3.2 That carer support need assessments consider a range of factors, including:
 - Current coping levels, ability to continue caring
 - Safety and exposure to risk
 - Education and support needs (i.e. coping/problem solving strategies)
 - Respite
 - The role of specialist support services, such as counselling, psycho-education, peer support, family therapy, financial and material aid, housing and legal support.
 - The impact of cultural and linguistic diversity.
- 3.3 That carers' experiences of service delivery are sought from MH and AOD services, and carers actively engaged in service quality improvement processes. Such systemic engagement may be enabled through the involvement of Carer Consultants in service quality improvement, or more broadly through the engagement of carer service users. The recently evaluated Mental Health Experience Co-Design initiative (MH ECO) ⁽²⁹⁻³⁰⁾ is a collaborative *consumer and carer inclusive* quality improvement methodology that may assist MH and AOD services towards achievement of these aims.

Recommendation Four:

Provision of information and carer support

4.1 Comprehensive and integrated dual diagnosis information

4.2 Assistance to develop improved communication, coping and problem solving strategies and strengthened limits and boundaries

Providing care and support to individuals with co-occurring mental health and substance disorders can pose a multitude of challenges for carers. Information in the early stages of diagnosis and service delivery (when consumers and carers are often most vulnerable) is particularly important, as is the need for integrated information about the interrelationships between mental health and substance use related behaviours and symptoms, and support to strengthen carers' coping, problem solving and communication strategies.

The following strategies are recommended:

- 4.1 That the information and support provided to carers address the following:
 - The symptoms and behaviours associated with a variety of mental health and substance disorders
 - The interrelationships and correlations between mental health and substance use behaviours and symptoms
 - Reasonable expectations for treatment and recovery

- Ways of supporting consumers to access support
 - Risk assessment and crisis management strategies
 - Adaptive communication and problem solving strategies
 - Implementation of limits and boundaries
 - The importance of self-care and carer safety
 - Options for carer support
 - The role of a carer's own beliefs, culture, past experiences, traditions and values
 - Ways of promoting consumer independence and recovery
 - Behaviours that may inadvertently support continued substance use.
- 4.2 That clinicians and support workers provide direct information and support to carers and *facilitate* referrals to other programs and services when more comprehensive and targeted support is needed, as detailed in Strategy 2.2.
- 4.3 That clinicians and support workers assist carers *to make sense of, and consolidate complex or disparate sources of information*, and support them *to implement strengthened coping strategies consistent with their beliefs, values, strengths and individual circumstances*.
- 4.4 That clinicians and support workers acknowledge the inherent complexities associated with dual diagnosis, and respect that carers are often doing the 'best they can' at any given time with the resources and knowledge available to them. That workers foster supportive *non-blaming* relationships with carers as a basis for assisting them to develop strengthened coping and caring strategies, and improved understanding of their family member's dual diagnosis experiences.
- 4.5 That MH and AOD services work in partnership to provide integrated dual diagnosis information and psycho-education forums for carers and families associated with their services. For example, this may entail an AOD service providing information about substance use at an AMHS carer support group.
- 4.6 That the VDDI Dual Diagnosis services assume an active role in the provision of information and support to families and carers. This may entail the direct provision of psycho-education and information services for carers, or collaboration with existing carer-focused services and programs in their provision of information and support.

Recommendation Five:

Greater support for carer inclusive practice in PDRS services, in the context of the recovery model

Carers indicated that their wider engagement with PDRS services could be particularly strengthened. Lack of expertise in family-inclusive practice methods, limited access to resources and concern that family work had the potential to undermine the delivery of recovery and consumer-focused support were cited as particular barriers impeding broader engagement with carers and families by service staff.

The following key strategies are recommended:

- 5.1 That training is provided to PDRSS staff to support more confident, routine and effective use of family-inclusive practice within a context of consumer recovery and empowerment. That such training addresses how carer/family engagement can positively contribute to strengthened recovery outcomes, and provides an open, interactive and respectful forum for staff to discuss their concerns, ideas and practice experiences.
- 5.2 That support workers receive training in *periodic* single session family consultations to engage carers in a manner that is both *consumer-focused* (consistent with the PDRSS sector's practice philosophies) *and carer/family inclusive*. That sessions are utilised to enable carers to discuss their concerns, contribute to risk and recovery planning, provide information, discuss their own support needs, and to develop an improved understanding of the role and objectives of the recovery paradigm. That these forums are also

used as a collaborative and mediated space for consumers and carers to problem solve and discuss mutual expectations^{vi}.

- 5.3 That systemic support for carer engagement be reflected in the form of organisational policies, procedures and guidelines. That such systemic involvement extend to carer participation in service quality improvement processes, as detailed in Strategy 3.4.

Recommendation Six:

Funding for a range of carer and family engagement activities across MH and AOD services

Whilst collaboration and engagement with carers and families is widely endorsed by State and Commonwealth governments^(2, 23-28), the findings of this report suggest that the practice of such engagement 'on the ground' is variable within services, and across service contexts. Limited funding and resources were considered key factors impeding more meaningful engagement with carers by many staff, as were funding agreements that do not support one-on-one engagement with carers/families as a funded service activity^{vii}.

The following strategies are recommended:

- 6.1 That the funding agreements governing the delivery of MH and AOD services enable and support a variety of carer engagement activities, *including the provision of one-on-one support to carers and families*. Such direct one-on-one engagement may include phone calls with carers, information provision, needs assessments, direct consultation with carers/families or any complementary support work undertaken to respond to carer/family support needs (e.g. referrals to carer support groups and services).
- 6.2 That MH and AOD services allocate funding for staff training in family-sensitive practices and family consultation, as outlined in Strategy 2.3.

Recommendations 7-10: Systemic strategies for strengthened integrated service delivery.

Recommendation Seven:

Strengthened collaboration between MH and AOD services

Supporting a family member's use of multiple services can place considerable burden on a carer's time and resources. Poor collaboration between MH and AOD services has the potential to place responsibility for treatment integration upon carers: including the co-ordination of, and provision of travel for multiple appointments, the provision of information between services and the provision of support for family members to pursue/follow through with referrals. Moreover, when consumers become marginalised from services greater responsibility can fall upon families to provide alternative forms of continuous care and support.

The following key strategies are recommended:

- 7.1 That MH and AOD services establish collaborative service protocols and partnerships to support and guide service integration from the point of service entry.
- 7.2 That MH and AOD service staff actively facilitate referrals between services, and (with consumer consent and participation) provide integrated treatment and support via collaborative treatment planning and reviews, information sharing, secondary consultation and the delivery of collaborative sessions with multiple professionals.

^{vi} Refer to McKenzie's *The Holding of Hope: Exploring the relevance of the recovery vision for carer/families*³¹, for a further discussion of family-inclusive practice in the context of recovery.

^{vii} Recommendation 15 of VAADA's *Submission to the 'Inquiry into the Impact of Illicit Drug Use on Families*¹², similarly identifies issues of capacity and resourcing as barriers impeding consultation with, and advocacy for families within AOD services.

- 7.3 That the training provided to MH and AOD services by the VDDI *recognise the impacts on families and carers associated with dual diagnosis and the role of family sensitive practice methods in the delivery of effective dual diagnosis interventions.*
- 7.4 That MH and AOD services *work in partnership with* carers and families to support consumers' effective use and engagement of multiple services.

Recommendation Eight:

Improved access to flexible substance use treatment and support for individuals with severe mental health issues and disorders

Access to effective AOD treatment and support for consumers with severe mental health issues was a cause for concern for many carers. Lack of service flexibility, capacity and expertise were cited as particular barriers.

The following key strategies are recommended:

- 8.1 That MH and AOD services (including residential detoxification and rehabilitation services) develop improved capacity, flexibility and expertise to meet the complex support needs of individuals with severe mental health issues in the routine delivery of services.
- 8.2 That all staff employed by MH and AOD services receive comprehensive support and training to provide sensitive and flexible treatment and support services to individuals with co-occurring severe mental health and substance use issues.
- 8.3 That specialist dual diagnosis services assume a role in the provision of support and training to MH and AOD services towards achievement of these aims.
- 8.4 That MH and AOD services *collaborate with carers and family members* to support individuals with severe mental illness more effectively access and utilise substance use treatment and support services.

Recommendation Nine:

Improved access to supported housing for individuals with co-occurring disorders an immediate priority

A lack of safe, supported and stable housing for individuals with complex health needs can place an unacceptably high burden of care upon carers and family members, often to the detriment of a carer's own health, safety, financial security and wellbeing. Without safe, supported and stable accommodation individuals with dual diagnosis may face a multitude of adverse health and social outcomes, including increased risk of relapse, self-harm, continued substance use, homelessness and poor prospects for recovery. The ongoing support provided by carers and families can play a critical role in the mitigation of such outcomes.

The following key strategies are recommended:

- 9.1 That Governments and services immediately prioritise increased access to stable, supported and recovery-focused housing for individuals with complex mental health and substance use issues. That such housing is made available across the community embedded in a variety of established areas and demographics.
- 9.2 That MH and AOD services work collaboratively and actively with community housing services to support consumer's access to supported accommodation. That access to supported independent housing is made a priority for consumer recovery.
- 9.3 That MH and AOD services recognise and assess the impacts on carers and families associated with providing continued housing support to consumers with dual diagnosis, and if required, implement appropriate carer support strategies.

Recommendation Ten:

The provision of psychosocial treatment and support

The importance of recovery-focused service delivery resonated strongly for carers; with substance use behaviours particularly associated with social factors (such as exclusion, isolation and boredom), and issues of poor self-esteem, lack of activity and lack of purpose. It was considered critical that MH and AOD services address such issues in their provision of effective treatment and support for consumers with mental health issues to mediate the potential for continued substance use and dependence.

The following key strategies are recommended:

- 10.1 That the treatment and support provided by MH and AOD services for individuals with co-occurring mental health and substance disorders balance medical and psychosocial models of treatment, rehabilitation and recovery.
- 10.2 That MH and AOD services support consumers to develop individual goals and plans for treatment and recovery that take into account their strengths, interests and hopes for the future, their development of independent living skills (such as financial management skills, and responsibility for maintaining ones' own safety and avoid risk), access to supported work, study and training opportunities, engagement in the community, and the importance of socialisation and personal relationships.

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6. Appendices

Appendix A: Recruitment processes undertaken at participating services.

North West Area Mental Health Service (NWAMHS)

Carers were recruited from the service's Continuing Care Teams (CCTs) based at their Coburg and Broadmeadows sites. The service's Carer Consultant approached multiple carers both over the phone and during the service's carer support group, and then provided interested candidates with a hard copy of the project information sheet. As a suitable number of carers were obtained using this method, the involvement of clinicians employed via the CCTs was not required to aid further carer recruitment. Carer interviews were undertaken at the service's Broadmeadows and Coburg sites, and the service was not notified of the identity of the final carer participants.

Neami PDRSS

Carers were recruited with the assistance of key workers from multiple service sites, as well as more directly by the researcher via attendance at a carer support group associated with the service. Key workers were asked to examine their caseloads and distribute information about the project to any carers who they believed fulfilled the project criteria. The researcher attended the carer support group (with prior permission from carers) in order to maximize carer recruitment; this proved to be an effective strategy yielding additional participants to supplement those recruited directly from key workers alone. Carer interviews were undertaken at two Neami service sites, and at carers' homes. The service was not notified of the identity of the final carer participants.

Mental Illness Fellowship, Well Ways Duo Program

Carers were recruited from the service's Well Ways Duo program – a 6 week peer-led group education and support program for carers and families of consumers with a dual diagnosis. The program's co-coordinator provided written information about the project to a subset of carers who had taken part in the program over the last 12 months (approximately 50 carers). This subset was limited to carers living in the same geographical areas within which the NWAMH and Neami services operate. Carer interviews were undertaken at carers' homes, and the service was not notified of the identity of the final carer participants.

Appendix B: Carer Interview Schedule.

Interview Script:

I would like to begin by asking some questions about your family member's/ friends experience of dual diagnosis.

1. How long has a dual diagnosis been a part of your family member's /friend's life?
(Prompts: timeframe, how did it evolve, warning signs, pathways to diagnosis)
2. How has a dual diagnosis affected the life and wellbeing of your family/member friend?
(Prompts: treatment, relapse, physical, social, emotional, financial, education, risk, prejudice)

The next set of questions offer an opportunity for you to discuss your experiences of being a carer to your family member/ friend with a dual diagnosis, and your own support needs.

3. What have been the biggest impacts of a dual diagnosis on you as a carer?
(Prompts: physical, social, emotional, relationships, financial, employment etc)
4. How has a dual diagnosis affected your other family members? (Prompts: physical, social, emotional, financial, employment)
5. How has a dual diagnosis affected your relationship with your family member or friend?
6. What types of support do you provide to your family member/friend with a dual diagnosis?
7. As a carer of a family member/friend with a dual diagnosis, how would you describe your own support needs?
8. How has the mental health service addressed any of these support needs?
9. Have you received support from other services to meet these needs?
10. In what ways has the mental health service assisted you to understand your family member's/friend's substance use, and its effects on his/her mental health? (Consider: information specific to substance use and impacts upon MH, debriefing, counselling, support, referrals etc)
11. In what ways has the mental health service assisted you to respond to your family member's/friend's substance use, and its effects on his/her mental health? (Consider: information specific to substance use and impacts upon MH, problem solving strategies, communication strategies, debriefing, counselling, support, referrals etc)
12. In what ways would you like to contribute to, or be involved in your family member/friend's dual diagnosis treatment and recovery?

Consider:

- i. Ongoing psycho-education, including information about substance use and its effects on mental health, treatment, behavior and recovery.

- ii. Assistance to develop effective problem solving strategies, improve communication, set boundaries and practice self-care.
- iii. Assistance to contribute to, and understand your family member's/friend's treatment and recovery (i.e. 'be part of the treatment team').
- iv. Collaboration with the mental health and AOD treatment teams.
- v. Family sessions or involvement in family therapy.
- vi. Information and referrals for substance use related services (for both consumer and carer).
- vii. Financial, legal and practical support
- viii. Access to dual diagnosis support groups

13. What do you think may be the benefits of such involvement? (Prompts. For the carer, for the consumer, for the mental health service)

The last set of questions will explore the mental health treatment and other support your family member friend receives for his/her dual diagnosis.

- 14. What support and treatment does the mental health service provide to your family member/friend? (Prompts: Medication, crisis support, case management, counseling, referrals, activities)
- 15. In what ways has the mental health service identified and responded to your family member/friend's substance use?
- 16. How effective do you believe this response has been?
- 17. How do you believe your family member/friend's substance use has affected his/her mental health treatment and recovery?
- 18. Does your family member/friend receive support from an alcohol or other drugs service? (Prompts: Counselling, detox, rehab, crisis support, gp, nurse). If yes, how does this service collaborate with you or the mental health service?
- 19. What support does your family member/friend receive from other sources? (Prompts: Friends/family, rehab services, employment service, social groups, self-help group)
- 20. What do you think the mental health service is doing well with regard to meeting the needs of consumers with a dual diagnosis?
- 21. How do you think the mental health service can better meet these needs? (Prompt: Support to consumers, support to carers, quality of service, involvement of carers)
- 22. Considering all that we have discussed, what do you think are the key factors for mental health services to consider in the care they provide to persons with a dual diagnosis?

Carers' experiences of providing care to a consumer with a dual diagnosis, and their involvement in mental health service delivery

Interview themes for discussion:

The following three themes were selected from the 12 qualitative interviews conducted with carers of a consumer with a dual diagnosis. These themes were chosen on the basis of their frequency across the interviews, and their poignancy and relevance with regard to service quality improvement. A more detailed and complex exploration of the wider interview themes and findings will be available to staff in the form of the final report.

1. Carers assume a significant protective role in the lives of consumers with a dual diagnosis. Examples include reducing risk taking behaviours and mediating their impacts on consumer safety and wellbeing, providing a safe place to live, setting boundaries around substance use in the home, advocating for loved ones in the legal system and responding to overdoses
2. Carers have an in-depth and complex understanding of their loved one's experience of dual diagnosis (including behaviours, symptoms, impacts on functioning, goals, strengths, coping mechanisms, helps, hindrances etc). Involving carers in service delivery was seen as a way of improving the quality and effectiveness of the treatment and support provided to consumers
3. Carers require information and support from mental health services to develop sensitive and effective problem solving and coping strategies. These are required to respond to situations and behaviours associated with dual diagnosis that are often complex, overwhelming, traumatising and unsafe.

Discussion Group Questions:

The group will be asked to consider each theme with regard to the following questions:

1. What has been your experience in relation to this theme or issue?
2. What do you believe the service is currently doing do address this item or issue?
3. How could the service better respond to this item or issue?