Best Models for Carer Workforce Development: Carer Peer Support Workers, Carer Consultants, Carer Advocates and Carer Advisors

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Contents

Definitions

Carer – There is no single definition of a carer (Clements, 1996). In this report, the term carer is used to refer to people who provide practical and emotional support to a person with mental health issues on an unpaid basis, such as relatives, partners, friends or neighbours. A carer may or may not live with the person they support and they do have to be identified by the individual with mental health issues to be their 'carer' (NCCSDO, 2008).

Consumer – A person diagnosed with a mental illness who uses mental health services.

Family/carer peer worker – This term is used to refer to workers in a range of positions for which lived experience as a family/carer of a person with mental health issues is an essential or desired criteria.

Peer Support – 'a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful … It is about understanding another's situation empathetically through the shared experience of emotional and psychological pain' (Mead, 2003, p.1).

> Also referred to as:
> **Mutual support** – A service type that is based on promoting 'the shared experience of people affected by mental health conditions and promotes mutual support and community connectedness' (Mutual Support and Self Help (MSSH) Agencies Service Development Plan, 2004).
> and
> **Self-help** – 'services are designed to encourage people to be active in their own recovery, and support an holistic approach to improve mental health, emotional wellbeing and quality of life' (MSSH Agencies Service Development Plan, 2004).

Peer worker, peer workforce – In this report, these terms are used to refer both consumer and family/carer peer workers.

1. Introduction

Project purpose

Currently, the primary mechanism for carer involvement in mental health services in Western Australia is a 'carer representative' model, in which carers are paid certain costs to sit on Committees, Boards, Advisory Bodies and similar to provide carer input.

In 2010, WA's first Carer Consultant was employed in the Southern Metropolitan's Area Health Service's Peel and Rockingham/Kwinana (PaRK) Mental Health Service, to provide family/carer support and education input across PaRK's health service.

Three or four other models of carer involvement that are being utilised in other jurisdictions, are in the private mental health sector in WA, or are being considered for implementation in WA. They are detailed below with an explanation as to what they do. (Note that these terms may be used to refer to different kinds of positions around Australia and internationally; the following descriptions are how these terms are defined and used in this document.)

- **Carer Peer Support Worker** – This is where carers receive services from other carers with 'lived experience' as a family/carer for a family member or significant other with a mental illness, rather than from a trained counsellor or support worker. They are trained and/or are qualified in peer work designed specifically for mental health carers.
- **Carer Consultant** – These are carers paid to support mental health carers, primarily when they are in clinical mental health settings. They also carry out systemic advocacy work to improve service responsiveness to family/carer needs. They are usually attached to individual hospitals or community mental health facilities.
- **Carer Advocate** – These are workers who provide individual advocacy for mental health carers who are experiencing difficulties in navigating the system or have issues where they need an independent advocate. Ideally, they have a social work, legal or other relevant background. Lived experience as a family/carer may be 'desirable' but not 'essential' criteria. ARAFMI WA has a part-time Carer Advocate currently.
- **Carer Advisor** – This is a proposed position within the Mental Health Commission, intended to provide advice on mental health carer policy and related issues.

Taking this into account, there is an identified need in Western Australia to develop a body of knowledge around carer needs, peer support, participation, advocacy and mentoring models. There is a need to seek broader sectoral involvement and service mapping to assist in workforce development and planning for carer services within Western Australia.

Accordingly, the purpose of this project is to:

- Review the literature for evidence to ascertain best practice models for mental health Carer Peer Support Workers, Carer Consultants, Carer Advocates and Carer Advisors and to make available evidence for future workforce planning and development; and
- Increase appropriate carer support, participation and advocacy within a Western Australian context via the development of evidence-based and replicable implementation models.

2. Methodology

The overarching purpose of the project is to:

- Review the literature for evidence to ascertain best practice models for mental health Carer Peer Support Workers, Carer Consultants, Carer Advocates and Carer Advisors and to make available evidence for future workforce planning and development.

- Increase appropriate carer support, participation and advocacy within a Western Australian context via the development of evidence-based and replicable implementation models.

Literature Review

A review of literature of published empirical works in the area of carer issues and carer interventions was carried out, using electronic databases Medline and PsychInfo to provide a wide coverage of citations and abstracts from psychological, health and medical journals internationally. Keywords used to guide the literature search included:

"peer support model"
"peer support and carers/care-givers"
"self-help and carers/care-givers"
"advocacy" "carer advocacy model / program"
"participation models" carer participation
"carer consultant"
"service models carers/care-givers"

An internet-based search (using the Google search engine) was carried out into the main family/carer support organisations and advocacy groups, at a local level and nationally, to locate key publications and projects, to map carer services and experiences and to devise evidence-based recommendations based on needs.

Stakeholder Consultations

Telephone interviews and feedback forums with key stakeholders were carried out by ARAFEMI Victoria staff to collect more detailed information on best practice implementation, current service frameworks, identified service gaps, current Western Australian and national models, sectoral readiness and capacity to assist in the design of evidence based models for carer services. Key stakeholders identified include:

- Mental health family/carers
- Mental health services (public and private sectors)
- Family/carer services (general and mental health specialist)
- Government bodies with responsibility for mental health
- Carer/peer workforce

Consideration of the following areas for recommendation were incorporated into the project:

- Consider a theoretical model for exploring carer peer support, advocacy and consultative roles as part of the broader mental health system framework

- Implications for service integration: identification of sector capacity and workforce development needs
- Identification of worker selection processes and training and development implications
- National benchmarks for effective development of carer based programs across the four identified service models.

Mental Health 2020: Making it personal and everybody's business

The Western Australian Mental Health Commission strategic policy document *Mental Health 2020* (Mental Health Commission, Government of Western Australia, 2011) was released after ARAFEMI Victoria staff carried out stakeholder consultations in Perth. Accordingly, it has been incorporated into the literature review but was not specifically discussed in the stakeholder consultations.

Deliverables

This project sought to further explore best models of practice for Carer Peer Support Work, Carer Consultant, Carer Advocate and Carer Advisor workforce development. The project outcomes include:

- Academically rigorous review of the literature on these carer involvements
- Service map and review of current models within the WA and broader Australian contexts
- Consultative forums with identified stakeholders including: family/carers, mental health family/carer organisations, Area Health Services and policy stakeholders to further explore best practice implementation
- Identifying service gaps to assist in the design of evidence based models for carer services
- Recommendations are made in light of this review of literature, within the context of current Western Australian and national models alongside feedback on sectoral readiness and capacity.

Timelines

Engagement of research consultancy	May
Initial consultation and development of detailed project brief	May
Review of literature	June – August
Stakeholder consultations	September
Presentation of results	October
Tabling of project report	November 30th 2011

Scope of Report

Inclusions:

The report will be limited to the terms of reference and areas of recommendation as outlined above. We note the overview of all family/carer positions is not exhaustive. Due to the large number and range of family/carer peer programs within the community sector, the large variation in titles and limited documentation of many services, the search focussed on developing a sample of established and emergent positions within the scope of project definitions. These factors mean the report draws primarily on Victorian literature, with information from other States and Territories included where possible.

In the emergent peer work sector, most of the literature focuses on consumer peer work which is generally more developed and researched than carer peer work. Accordingly, where useful and applicable (for example, in looking at workforce development) the review draws on consumer peer work.

Support groups also generally fall outside the scope of this report, however as the literature on peer support for family/carers almost exclusively investigates peer support as provided in support groups, this was included.

Exclusions:

'Carer representatives', family/carers who are paid certain costs (usually sitting fees) to sit on Committees, Boards, Advisory Bodies and similar to provide family/carer input are not addressed in detail in this report.

Other family/carer peer services currently being provided in Australia which are not within scope of this report include:

- Helplines
- Family/carer peer education programs and workshops (such as the Mental Illness Fellowship's 'Well Ways' and 'Well Ways Duo' and programs provided by ARAFEMI/ARAFMIs and other non-government organisations)
- Family/carer researchers and facilitators of quality improvement activities

There are also many family/carers doing volunteer work in mental health services, however this report focuses on paid roles.

Terminology

It is noted that many family/carers do not identify with the term 'carer,' preferring to be referred to as a consumer's mother, father, partner, brother, sister, friend, neighbour etc. Many consumers also do not like the word. However there is a need for a general term to refer to people providing unpaid support and care to people with mental health issues and a body of knowledge and has developed around the term 'carer.' Accordingly, the terms family/carer and carer are used interchangeably in this report.

3. Literature Review – Part I

Overview of family/carer experiences and needs

There is a growing amount of literature that portrays the difficult experiences of family/carers of people with mental illness. These range from anecdotal carer stories (collections of 'lived experience'), support and information booklets and research into the needs of carers. This literature predominantly focuses upon the symptoms and impact of low prevalence disorders (psychotic disorders) and the difficulties in accessing support for someone in the acute phase of illness, also referred to as the 'burden of care'.

In research carried out by Carers WA, family/carer described their experiences of caring as follows:

> *"Providing love and support … valuing and honouring your loved one in a way no one else can."*

> *"At times I feel overwhelmed by sadness for my son…"*

> *"Generally* [I experience] *a feeling of never being able to be happy and carefree."*

> [I'd like] *"…that the carers voice would be heard before one has become hoarse from yelling for help"*

(McKeague, 2003, pp.11-13, 40 and 47)

Caring for a friend or relative who has a mental illness can be felt as a double-edged sword: driven by love and simultaneously weighed down by it. Carers can strive for hope and help, while being flooded by frustrations and disappointments in the face of the illness reality and less than adequate supports and services.

Mental illness – prevalence and social impact

More general data on disability and chronic illness reveals that there are increasing numbers of people with disability and chronic illness (Cummins, Hughes, Tomyn, Gibson, Woerner and Lai, 2007) and the prevalence of mental illness has risen to 1:4 in the last decade. Though statistical data captures those that meet the criteria for diagnosable mental illness, they do not reflect the true impact on the quality of life of those experiencing mental health problems (Robinson et al., 2008). Mental illness is the leading cause of non-fatal disease burden in Australia (Mathers, Vos and Stevenson, 1999), a significant cause of death (suicide 2%) and has major implications on economic and productivity burden, reflected in data on lost work days (Lim, Sanderson and Andrews, 2000).

The role of family/carers

The role of carers has changed over the past three decades, with a dramatic escalation of community care roles in the past ten years. These changes have been driven by three main forces: greater sophistication of psychotropic medication reducing length of hospital stays, increased awareness of the negative consequences of long hospitalisations and the costs of providing care (Leggatt and Player, 1997; Robinson, Rogers and Butterworth, 2008). Deinstitutionalisation, social

policy involving a shift away from long term institutionalised care, government policy shifts and shorter periods of hospitalisation have led to an ever increasing demand for community care.

Most people with a mental illness live in the community with informal carers such as family, friends, neighbours and co-tenants. Australian Bureau of Statistics data indicates that 60% of carers provide ongoing care for periods of five years or more (ABS, 2004). The cost of caring and the economic, social and psychological consequences are major social health issues represented across major population surveys (ABS, 2004; AIHW, 2006b).

"The movement towards deinstitutionalisation has in general imposed on families a caregiving role for which they are unprepared, untrained and from which they have been systematically excluded in the past." (Lefley, 1991, p.1)

In a discussion of family relationship services, Robinson et al. (2008) identify that the high population burden of mental disorders is significant in family relationships for the following reasons:

(1) *Mental disorders impact not just on the individuals affected but also on those around them - including immediate family and other relatives - and may be both a cause and a consequence of family/relationship difficulties.*
(2) *Although most common mental disorders are amenable to treatment, the majority go undiagnosed and untreated.*
(3) *Many disorders are chronic or recurrent and they often call for long-term management, not just acute care.*
(4) *Much of the care provided for people with mental disorders (even very serious disorders) is informal care provided by family members.*

(Robinson et al., 2008, p.4)

The impact of caring for people with a mental illness

Family/carers face ongoing difficulties beyond accessing support and care for their loved one. Carers must come to terms with a range of emotional and coping responses including shock and grief ("how can this have happened?"), guilt ("could I have prevented it?") and frustration at the lack of ability to cure or assist their loved one that can impact at a more personal level (Alexander, 1991; Pagnini, 2006).

Living with a person with a severe mental illness can impact significantly upon the family and can affect relationships, financial status, work, leisure and the mental and physical health of family/carers (Baronet, 1999). Purves (2002) found that carers often feel a sense of distress and isolation as they strive on two fronts: first to understand their relative, who may have confused thoughts and show erratic behaviour, and second, to advocate on their behalf during intermittent contacts with health services. This dual role is often difficult and stressful. SANE (2007) research indicated that up to 40% of carers experience mental health issues themselves as a result of caring. In a study by Cummins et al. (2007), carers were found to have lowest wellbeing scores of any Australian population group, with 60% of carers reporting significant depression and life impacts.

(Note that subjective wellbeing is described as different from happiness, in that happiness can come and go in a moment. Wellbeing is a more stable state of being 'well' and feeling contented

(Cummins, Hughes, Tomyn, Gibson, Woerner and Lai, 2007). Wellbeing tends to be a broader and more encompassing concept that takes into consideration the 'whole person.' Beyond specific physical and/or psychological symptoms or diagnoses related to health, therefore, *wellbeing* is used as appropriate to include context-free measures of life experiences (e.g. life satisfaction, happiness) (Dana and Griffin, 1999, p.364).)

Focussing on anxiety, depression and eating disorders, the experience of carers of people with mental illness is summarised in the following statement, an excerpt from a paper produced by the Victorian Mental Health Carers Network's High Prevalence Disorders Project Working Group:

The main findings established by the research were that carers and families experience significant and comprehensive impacts. The research showed that people with these disorders often become highly dependent upon carers (spouses, parents and children) and other family members, leading to a traumatised family system in which crises and tension in relationships are common. The symptoms of the disorders, and accessing treatment, often become the central point around which family life revolves. Physical and emotional exhaustion, chronic stress, depression and grief are commonly experienced by family members and carers may become inextricably involved in compulsive, avoidance and other symptom related behaviours. Social isolation and low self-esteem, economic losses, decreased life opportunities, and difficulties accessing effective treatment and support services all add to the pressures that carers and families experience. Most carers received limited information about their relative's illness, its management and services that can assist themselves or the person they support (I'Anson, 2004).

Literature on carer supports

Whilst the majority of papers focus on the burden of care, there are a number of research papers looking at the specific service needs of carers and with the growth in carer programs, there is an emergence of useful comparative data on carer need and service impact. The earliest efforts at carer based interventions are articulated well in the '14 Principles for the Relatives and Carers' (Alexander, 1994), which urges carers to seek useful supports, information and peer supports to assist them on the journey of caring. Clear information, involvement in planning, support to increase coping and resilience and appropriate supports at times of acute mental health crisis are consistently indicated across the research (Woof Schneider, 2003). Lauber et al. (2003) found that support to assist carers to deal with specific issues that caused burden such as dealing with threats and challenging behaviours, management during crisis and supporting carers to address barriers to social contact and leisure were helpful to wellbeing.

Most of the more recent studies on carer needs focus on the expectations and experiences of families in relation to community mental health service provision (Hodgson, King et al., 2002). Spear (2003) investigated the level of satisfaction of carers in relation to key components of mental health service delivery, particularly in the relationship between the principal service provider and the carer role in care coordination. They found that there were different information needs between consumers and carers (Spear, 2003). Other research identifies that there were differences in burden

according to carer relationship (Ostman and Walllsten, 2005) and differences in need due to the level of burden experienced by the carer (Lauber et al., 2003; Hodgson et al., 2002). Applicability of carer interventions was also found to differ across indigenous communities (Phillips, 2004) and culturally and linguistically diverse (CALD) groups (Rooney et al., 2006) where further barriers to understanding, attitudinal bias (towards consumers fand families) and difficulties in accessing appropriate services may also need to be taken into account. The literature on carer interventions also notes that clear results on what interventions are most useful are affected by poor response rates, carer availability and variations across socio-cultural groups which make generalisations difficult (Cummins et al., 2007).

Arksey (2002) found that there was little evidence to show that the support services recommended by government as crucial to carers, such as short breaks, were effective. However, these findings highlighted difficulties in utilising standard assessment tools rather than undermining the value of services. For example, the use of standard pre and post test measures of effectiveness (using constructs such as carer burden, stress, physical health, and emotional wellbeing and/or depression levels) gave results that were at odds with the expressed levels of service satisfaction reported by carers. Even where no evidence of change was identified via standard testing, carers may have felt satisfied with the service provided. The findings also indicated measures of knowledge had similar discord with carer service satisfaction (Arksey, 2002). The findings suggested the use of broader view measures that explored the benefits for carers, benefits for the person supported, benefits for the family as a whole, factors impacting on service usage and long-term outcomes for society. Whilst the situation (for the person with the mental illness) may not change, the carer may have felt supported and connected with a service, have better ability to navigate systems and find support and ultimately felt cared for in themselves (Arksey, 2002). Whilst the wellbeing of the carer is ultimately tied to the wellness of the consumer (Pagnini, 2005), this skew needs to be accounted for in evaluative design.

Results also indicated that number of referrals or service usage statistics were poor indicators of benefit as compared to levels of service satisfaction. Carer involvement in designing the questions to be asked was effective in developing viable evaluation. A key message from the study was the importance of using diverse research methods to increase the depth and breadth of data collected, as well as adopting more innovative and inclusive research designs such as structured interviews rather than standard outcome measures (Arksey, 2002).

The Carer Life Course Framework (Pagnini, 2005) builds on such research and extends carers' needs into a theoretical framework for understanding aspects of caring over a continuum of needs, external factors and time. This model can be utilised by services to ensure that support interventions are appropriate to carers, taking into account their place in the caring journey, their life stage and relationship with the person with the mental illness. It recognises that caring is not a linear process, but rather one that changes, is individual and one that has stages of variant need. This model was further explored in a 2007 study to ensure validity across different community contexts (Sanders, 2007).
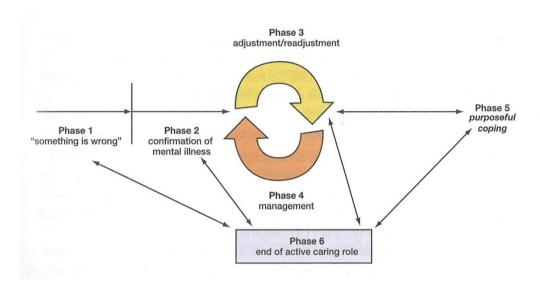
Diagram extracted from Pagnini, 2005, p.23

The framework describes six distinct phases that many carers go through on their caring journeys. As these are experienced by many carers they are described as 'constant across phases.' These constant phases are described pictorially above. In addition, it allows for understanding the different needs and experiences of different types of carers according to relationship, life course/life stage and resources available. These are described as variables that may impact on a carer's experience. The model also explores the impact of the consumer's degree of wellness on the carer's wellbeing, the impact of other relationships on carer well being, the ongoing grief and loss, the ongoing need for support, the impact on financial resources, the need for carer input, fear about the consumer's safety and needs for ongoing planning. These aspects are consistent with the research and anecdotal evidence already discussed.

The benefits of actual mapping of the carer journey can assist carers by normalising what is often a frightening and isolating journey. The research aims to provide a map of what other carers have gone through, along with links to relevant information and support services. Such evidence is also useful for policy and government organisations in constructing an evidence-based system of carer support, identifying gaps and developing responses to ensure carers' needs are met. It also supports services by demystifying the carer experience and enabling service providers to provide the most effective interventions at the most appropriate time (Pagnini, 2005).

Service delivery and family/carer inclusion

Much of the literature on caring for people with mental illness particularly discusses the impact on families of poor service delivery, lack of family involvement or inclusion by service providers, fragmentation of services and the lack of access to carer-specific supports. For instance, research conducted by beyondblue and the Victorian Mental Health Carers Network (2004) identified a set of needs which can be generalised to carers of both high prevalence and low prevalence mental illnesses. Their research explored the impact of mental illness from the carer's perspective, over time and in relation to policy and intervention outcomes rather than 'burden of care.' The needs identified by carers were for:

- Increased community awareness about signs and symptoms of mental illness to facilitate detection, early intervention and support.
- Increased recognition of the experiences and needs of carers and provision of information and referral for support.

- Increased recognition and assistance to overcome the impact of living with a person with mental illness (relationships, family dynamics, reduced level of intimacy, social and emotional distancing, restricted social relationships).
- Assistance with significant financial costs related to caring (including accessing treatment, demands of specific aspects of the illness, time off from work and ability to continue employment).
- Increased access to effective treatment via better knowledge and awareness, availability of information, increased awareness and skills among health professionals and effective early intervention or crisis management.
- Better inclusion of carers' needs and concerns – voice – and more inclusive approaches to treatment and management.

These same or very similar themes of need have been articulated, prioritised and reiterated across a

> *"I am wasting my voice, I am constantly being asked what my needs are and then my needs are denied – I have been doing this since my son was early teens – he's in his twenties now."*

number of small scale and large scale empirical studies over the past 30 odd years (Baker, 1977; Hatfield, 1979; Winefield, 1993; St-Onge and Lavoie, 1997; Knudson and Coyle, 2002; Provencher, Perreault, St-Onge and Rousseau, 2003; Fischer, Kemmler and Meise, 2004; Lloyd and Carson, 2005; Li, Lambert and Lambert, 2007). The following reports by key mental health bodies also describe these issues: SANE Australia (2007), Pagnini (2005), Victorian Mental Health Carers Network (2001), Mental Health Council of Australia and Carers Association of Australia (2000). The findings of these key researches into carer needs are consistent with the academic literature and include:

- "Targeted education/mental health promotion to families and general health and community services." (Victorian Mental Health Carers Network, 2001)
- "When carers are asked about their needs, they often first focus on services for the person with the mental illness/mental disorder. They then immediately mention information." (Pagnini, 2005)
- "Many health professionals still exclude family carers from treatment planning … Health professionals need training and supervision to ensure these attitudes to family carers are improved." (SANE, 2007)
- "Some carers reported that additional financial assistance would make their lives easier." (McKeague, 2003)
- "Respect as a carer from service provider." (McKeague, 2003)
- "The participants wanted structured programs that would address their needs for information about the mental illness/mental disorder and its treatment, how to manage symptoms, and how to relate better to the consumer, to other family members, and to health professionals. They also wanted to learn coping strategies, get support from other carers and have the opportunity to deal with their own issues in a therapeutic environment." (Pagnini, 2005)

Leggatt (1997; 2000) states that a further necessary step is for family/carer inclusion to become standard practice. She suggests that recognition of the lived experience of family/carers and consumers is essential for building collaborate partnerships with clinicians and needs to occur at a systemic level rather than occur as gap-fixing by individual services (Leggatt, 2000). Carer inclusive

practice has been proven to improve the long term health outcomes for consumers and carers (Falloon, 1998; McFarlane, 1995). In 2000, The Royal Australian and New Zealand College of Psychiatrists produced a range of guidance notes and suggestions for involving families, oriented at educating and supporting professionals. They clearly state the responsibility of services to engage families and carers in treatment and care (Royal Australian and New Zealand College of Psychiatrists and Ministry of Health, 2000). It is noted that further research in areas such as the impact of mental health and privacy legislation and efficacy studies (in relation to carer interventions) would be useful.

It is noted that in Western Australia, a series of consultations with family/carers about their experiences and needs has been carried out by the Mental Health Commission since its establishment in March 2010. This includes the widespread consultations carried out in the development of the *Mental Health 2020* strategic policy document, which sets out the directions for reform of the Western Australian mental health system in the next ten years (Mental Health Commission, Government of Western Australia, 2011). The family/carers who attended stakeholder consultations for this project mentioned the many forums which have been held and their concern to see the information they have provided translated into action.

Consumer and carer peer workforce

> *There are three major rationale that support the development of the service user workforce in the mental health sector. Philosophically it is the ethical thing to do. On a pragmatic level it is a sensible thing to do. On a policy level it is the expected thing to do.*

> (Mental Health Commission, New Zealand, 2005, p.5)

Many non-government community mental health services across Australia were originally established and operated by consumers and carers in response to deinstitutionalisation. This 'peer workforce' initially emerged as a consequence of need without formalised professional community support. Community managed services continue to recognise the value of peer to peer support as an important adjunct to both the clinical system and community sector (Bartolo and Sanders, 2008). Peer support models in community managed mental health services have 30 or more years of history and have been incorporated into broader funding models across Australia. This is captured in the *Charter of Peer Support* (Mutual Support and Self Help Network, 2011).

Consumer peer workers were first employed in Australian public mental health services in the early 1990s. The first Consumer Consultants were employed at Rozelle Hospital in Sydney in 1993. In Victoria, a series of 'remarkable' action research projects were carried out under the auspice of the Victorian Mental Illness Awareness Council from 1986. The longest study, the *Understanding and Involvement (U&I)* project, sought to establish processes through which staff and consumers could routinely collaborate to research and evaluate consumers' experiences of psychiatric hospital wards and make appropriate changes to hospital practice (Wadsworth, 2001). Employing consumers as staff was described as one essential aspect of bringing about collaborative, system-wide change.

> *The model hinges on there being consumer catalysts available in the system to bring about the changes proposed, to provide a critical bridge between both* staff *and* consumers *(being both* staff *and consumer themselves), to increase consumer feedback and staff-consumer communication, and to act as a catalyst and organiser to introduce more consumers to participation in comprehensive systems advocacy. These positions are paid work and are designed to be a permanent feature of a services system ...* (p.195).

The term 'consultant' was chosen as it was felt to be a 'dignifying' term, reflecting that consumers would be working alongside staff as equals and consultants on service development and quality assurance (Wadsworth and Epstein, 1996). The term had also been used by consumers doing similar work in Rozelle Hospital in Sydney and the United Kingdom.

Following this project, in 1996, government funding was provided for every Area Mental Health Service in Victoria to employ a Consumer Consultant. The first Carer Consultants and other paid family/carer peer work positions were established over the following decade.

Since then, the peer workforce has both seen many achievements and faced significant challenges. The introduction of the federally-funded Personal Helpers and Mentors (PHaMs) program in 2006 saw increased investment in and recognition of peer work roles in the community sector. Further resources and supports continue to be developed.

Policy overview: consumer and carer workforce

National and state government policy documents (as well as industry service standards) increasingly recognise the value and importance of employing consumers and family/carers in mental health services.

National

Actions of the Fourth National Mental Health Plan (Australian Health Ministers, 2009) include the following:

- *Adopt a recovery oriented culture within mental health services, underpinned by appropriate values and service models.*
- *Develop and commence implementation of a National Mental Health Workforce Strategy that defines standardised workforce competencies and roles in clinical, community and peer support areas*
- *Increase consumer and carer employment in clinical and community support settings*

Addressing 'Quality Improvement and Innovation', it states,

> *Although consumers and carers are employed in some service sectors, their expertise and utility is under recognised. Utilising the skills and knowledge of those with 'lived experience' has been shown to improve engagement and outcomes for people with mental illness in a range of settings. Consumers and carers should also be utilised in staff training programs and in staff selection processes. There are a variety of models of employment of consumers and carers in community and bed based settings, but this has not been systematically developed or implemented in Australia compared with other parts of the world. We do not have minimum standards to guide the number or available hours of consumer and carer support workers across the community and bed based sectors. We need to develop models that provide sufficient support and determine the role and responsibilities of peer employees. Suitable training, supervision and roles need further exploration. Development of a strategy needs to incorporate findings and proposals from other projects and national activity including developments related to accreditation and registration.* (p.51)

Indicators for monitoring change include the "proportion of total mental health workforce accounted for by consumer and carer workers."

The National Standards for Mental Health Services (Australian Health Ministers, 2010), Standard 3 requires,

> *Consumers and carers are actively involved in the development, planning, delivery and evaluation of services.*

Commitments to developing the consumer and carer workforce are also contained in the Council of Australian Governments (COAG) National Action Plan on Mental Health 2006-2011 and the National Mental Health Workforce Strategy (Mental Health Workforce Advisory Committee, 2011).

However, consumers and family/carers observe that policy commitments have not necessarily been translated into practice: implementation has been variable across service settings and significant barriers to meaningful implementation persist (Bennetts, 2009). The National Mental Health Consumer and Carer Forum (2010) notes that goals require "leadership, a strategic approach and the commitment of funding and other resources to ensure that they happen" (p.7).

Western Australia

The Western Australian Mental Health Commission outlines the direction for reform of the WA mental health system in its recent policy document, *Mental Health 2020: Making it personal and everybody's business* (Mental Health Commission, Government of Western Australia, 2011).

This document affirms the important role of family/carers play in the lives of many consumers, as "significant individuals who often provide strong and lifelong support to foster a good life. Service providers and community activities may change focus, staff and programs, but meaningful relationships with family and friends can sustain individuals experiencing mental health problems and/or mental illness for the long term" (p.8). It also acknowledges the difficulties family/carers can experience, including feeling "overwhelmed and powerless" (p.15).

Under 'Sustainable Workforce' (Action Area 8), *Mental Health 2020* identifies that the implementation of the reform directions "*requires a sustainable, well trained and capable workforce able to understand and meet the diverse needs of people with mental health problems and/or mental illness, their families, carers and communities.*" 'Looking forward' includes:

- *Peer support and mentoring as an accepted and valued part of mental health support and services*
- *Involvement of individuals and consumer and carer organisations in the assessment, planning, delivery and review of services*

The policy document also contains clear commitments to involving family/carers as well as consumers in the planning and delivery of mental health services. Key Principle 2, 'Engagement', requires,

> *People with mental health problems and/or mental illness, their families and carers are engaged as genuine partners in advising and leading mental health developments at individual, community and service system levels across Western Australia.*

This is reiterated under 'Good planning' (Action Area 1). 'Looking forward' includes:

Increased involvement of individuals, families and carers in the design of policy, planning and service delivery within mental health services and systems.

Action Area 9, 'A high quality system' highlights the role of the Mental Health Commission in "engaging people with mental health problems and/or mental illness, their families and carers as partners in the development of service systems, programs and individual services."

Mental Health 2020 was informed by the consultation paper released in 2010, *WA Mental Health Towards 2020: Consultation Paper* (Mental Health Commission, Government of Western Australia, 2010). This paper addressed the employment of consumer and carer peer workers, including the following:

In discussing consumer peer workers, the work required to support successful establishment of these positions was also acknowledged.

Action 1 Strengthen partnerships with consumers and families / carers / advocates in service planning, management and delivery

Initiative 1.1 Expand the involvement of peer support workers and consumer consultants

Initiative 1.3 Increase support available for carers, family and advocates

This included recognition of the role of family/carer peer workers,

Expanding the use of paid carer consultants would increase the support available for carers and families. Carer consultants have a good knowledge of the mental health system and the issues faced by families and other carers. They provide emotional support, information and referral to families and carers. They also work with mental health staff in developing services responsive to the needs of carers and families. Carer consultants would be employed by public mental health services or other service providers (eg NGOs). The Carer Consultant Network in Victoria is developing a model for Carer Consultant training which could be used in WA (pp.40-41).

Expanding the use of peer support workers and consumer consultants requires more than merely funding additional positions. Rather, the roles need to be recognised and embedded in the delivery of mental health services by:

- *defining the role of a peer support worker*
- *educating clinicians and mental health professionals about the benefits of peer support and recovery*
- *addressing issues of confidentiality and information boundaries*
- *ensuring that appropriate support mechanisms and supervision are structured throughout the program*
- *developing a consistent and effective training program for peer support workers*
- *integrating their role into the multidisciplinary teams in inpatient and community settings*
- *employing consumer consultants in every mental health service*

As the literature below attests, similar work is required in the employment of family/carer peer workers.

4. Service map: Peer workforce around Australia

In 2007-08, 25% of public mental health services nationally employed carer peer workers (39% employed consumer peer workers). There were 27 FTE equivalent carer workers across the 221 public mental health service organisations and 64 FTE consumer workers (Department of Health and Ageing, 2010). (Note: the number of actual workers is higher as peer workers in public mental health services are often employed part-time.)

The number of peer workers in non-government (community managed) organisations is unknown, however the work being done in organisations utilising peer support in a volunteer or paid capacity is extensive. The types of work being carried out include helplines, support groups, peer to peer counselling, support and peer mentoring programs (Bartolo and Sanders, 2008). Internet searches reveal this is consistent across mental health services in all Australian states and territories. The introduction of the Personal Helpers and Mentors program (PHaMs) has seen more than 260 consumer peer workers employed since 2006 (Mental Health Coordinating Council, 2011).

Total expenditure on Consumer and Carer Consultants, however, still represents a mere fraction of the total spending on salaries and wages in the mental health sector (Commonwealth of Australia, 2006, cited in Stewart et al., 2008). Initiatives to support and develop the consumer and carer workforce are most notable in NSW, Queensland, South Australia and Victoria (National Mental Health Consumer and Carer Forum, 2010). Initiatives in these states are set out below. A service map of key family/carer peer positions around Australia and internationally can be found in Table 1 at the end of this document.

Peer workforce in Australian States and Territories

New South Wales

Since 2005, NSW Health has funded the Family and Carer Mental Health Program. It seeks to address family/carers' needs by through three key initiatives:

- 'Family-Friendly' Mental Health Services – employing specialist staff to help make changes to work practices through workforce training and development and through specialist advice
- Mental Health Family and Carer Support – providing education and training packages and individual support services through specialist NGOs
- Generic Family and Carer Supports – improving awareness of and access to mainstream carer support services such as financial support, counselling and respite

Further detail on the first two initiatives is provided below.

'Family-Friendly' Mental Health Services

The Family and Carer Mental Health Program targets attitudinal and practice change within clinical mental health services as the first key plank of the service model. Under the Program, Area Health Services now employ specialist staff to facilitate changes needed to make mental health services more family/carer friendly. These family and carer specialists coordinate local training and resource development, and provide specialist clinical consultative advice and support about family intervention.

Currently, 2 FTE family/carer specialist positions are funded for each Local Health District plus 1 FTE based at the Transcultural Mental Health Centre, making a total of 17 FTE. NSW Health does not require family/carer specialists to have lived experience as family/carers; this is left to the Local Health Districts to determine.

The next focus for this program is intended to be in developing the training base of the program to educate clinicians further on the specific needs of families and carers from Aboriginal and CALD backgrounds, young carers, older carers, and families and carers of people who are in prison or of forensic consumers. Guidelines for the uniform recording of clinician contact with families and carers in Area Health Services are also to be developed (Personal communication, 23 November 2011).

Mental Health Family and Carer Support

The second key aspect of the program is the funding of direct support services for families and carers through NGOs. Four to five agencies are currently funded to provide new or enhanced services across the state. They deliver the following services and supports to family members and carers of people with a mental illness:

- Education and training packages which teach families and carers about mental illness and its management, and help to build coping skills and resilience
- Individual support and advocacy services for families and carers of people with a mental illness
- Assistance to establish peer support groups

The specific needs of families and carers from Aboriginal and Torres Strait Islander and CALD communities are being addressed through partnerships with other organisations which already have connections with these communities, through the employment of Aboriginal staff and through developing appropriate support programs directly with Aboriginal families and carers.

There are currently 48 FTE family and carer positions within these non-government organisations. Again, NSW Health does not require staff employed in these positions to have lived experience. ARAFMI NSW advises that many of its staff, including most support workers, have lived experience however this is not specifically required for the roles (Personal communication, 16 November 2011).

Future plans include a consolidation phase as potential new service providers develop and embed their services and successful existing service providers concentrate on their penetration with minority stakeholder groups including families and carers from Aboriginal and CALD backgrounds, older carers, young carers and families and carers of people who are in prison or of forensic consumers (Personal communication, 23 November 2011).

Queensland

The Queensland Consumer and Carer Workforce Network (CCWN) commenced work on consumer and carer workforce issues in 2007. Its aims were to:

- Examine existing workforce issues
- Consider ways to expand and enhance the consumer and carer workforce
- Clarify the role of consumer and carer workers within the mental health workforce
- Assist mental health services in establishing consumer and carer roles, and
- Offer a career pathway for this workforce

In August 2011, Queensland Health released *The Mental Health Consumer and Carer Workforce Pathway* ('the Pathway') (Queensland Government, 2011). This work:

> *aims to embed a consumer and carer perspective within mental health services through the engagement of staff who can role model these elements and provide a connection for consumers. ... An essential component of a consumer-focused and recovery-oriented mental health service is a workforce where the consumer, carer and family perspective is threaded through the planning, delivery and evaluation of services* (p.ii).

Queensland Health's Mental Health Alcohol and Other Drugs Directorate employs a full-time Senior Project Officer, Carer and Family Initiatives. In 2011, this is one of seven positions (6 FTE) in the 'Consumer, Carer and Family Team':

- Manager
- Administrative Officer
- Senor Project Officers
    - Consumer and Carer Workforce Network
    - Carer and Family Initiatives
    - Consumer Companion Program Statewide Coordinator
    - Consumer and Carer Workforce Supervisor
    - Consumer and Carer Representative Supervisor

It was planned to expand this team to include a Principal Project Officer with responsibility for the Consumer, Carer and Family Participation Framework Auditing, Recovery and Research.

The Position Description for the Senior Project Officer, Carer and Family Initiatives is contained in Appendix A (Carer policy advisor #1). This position requires lived experience as a family/carer, in line with the decision that this is now required for all consumer and carer positions:

> *Substantial debate has occurred around a mandatory requirement of the consumer and carer positions to identify as a mental health consumer or carer. To address these concerns the Consumer and Carer Workforce position descriptions now cite a lived experience or caring experience as necessary. However, individuals appointed to these positions must also have, as a priority, the required skills to undertake the role.*

(Queensland Government, 2011, p.8)

The Pathway provides a guide to the development of career opportunities and appropriate mechanisms of support for workers who have lived experience as a consumer or a carer. Current and proposed positions include:

- Consumer and Carer Representative
- Consumer Companion
- Recovery Support Worker
- Specialist Consumer/Carer Consultant or Coordinator
- Consumer/Carer Consultant
- District Consumer/Carer Workforce Coordinator

Descriptions of each of these roles are provided in the Pathway document. It states that ideally, a Carer Consultant position should be established to work alongside existing Consumer Consultants.

Consumer/Carer Consultants carry out systemic advocacy work. Position descriptions for Consumer/Carer Consultants and District Consumer/Carer Consultant Coordinators are contained in Appendix A (Carer Consultant #2 and Carer Consultant Co-ordinator #1).

The Pathway also describes work which has been completed or is planned in relation to supervision, Key Performance Indicators and the orientation of new consumer and family and carer workers. It also describes the CCNW, through which the approximately 52 consumer and carer workers members across the state meet monthly at Queensland Health. CCNW also holds an annual workshop to facilitate networking, ongoing training, information-sharing, support and planning for peer workers. In 2010, Queensland also initiated the establishment of a National Consumer and Carer Workforce Network (at a corporate level) which meets bi-monthly via teleconference (involving Queensland, NSW, Victoria, Tasmania and South Australia).

South Australia

A full-time Carer Consultant is employed SA Health's Mental Health Unit. This is a family/carer with lived experience who carries out policy advice and sits on various committees and working groups looking at sector reform. The Carer Consultant also convenes a Mental Health Unit Carer Advisory Group which meets monthly. It is planned that she and the Consumer Consultant will commence work on policies/guidelines/framework for the SA peer workforce in 2012.

There are currently 5 FTE Carer Consultant positions based in hospitals and treatment centres. (As some are part-time, there are currently 7 or 8 workers.) The Carer Consultants provide peer support for family/carers (note they do not carry out systemic advocacy work). Lived experience is required for these roles. Some NGOs also employ Carer Consultants.

In the Central North Adelaide Area Health Service project described above (Kling et al., 2008), Carer Consultants were employed in the region's acute units and several statewide specialist services. The Carer Consultants were supported by a staff mentor appointed by Carers SA, who assisted in recruiting, training and sustaining them in the roles. The training had a strongly educational approach, providing information on new resources and programs available to carers. In response to feedback from existing service staff, more extensive training and orientation is planned for future workers in these roles.

Victoria

Non-government organisations employ Carer Peer Support Workers and Carer Consultants. Mutual Support and Self Help (MSSH) (as peer support has been known) is a funded sector. One model of carer peer support is the Carers Offering Peer Early Support (COPES) program which has been developed in NSW and Victoria. Family/carer peer support workers are employed by a family/carer community mental health organisation and are based between an NGO and a hospital inpatient unit, enabling them to see family/carers in both settings. The supervision and support model is negotiated and determined in the program planning and set out in a Memorandum of Understanding and the Position Description. This type of program is outlined in the Eastern Health and Monash University evaluation (2009) and *Gathering Lived Experience, Phase II: Piloting the Peer Support Program* report (ARAFEMI, 2010). The evaluation of the Eastern Health program (Eastern Health and Monash University, 2009) found that both peer support workers and clients valued the immediacy of contact provided by having the workers based in the inpatients unit. However no clear consensus could be reached regarding the advantages and disadvantages of having the workers employed by an external organisation.

In 2009-10, the Victorian Department of Health provided approximately $36,000 per public Adult, Aged and Child & Adolescent Mental Health Service for the employment of family/carer consultants (Southern Health, 2010). Carer Consultants have established a professional association, the Carer Consultant Network of Victoria (CCNV). The Network meets monthly and has developed a series of training modules in collaboration with the Victorian Mental Health Carers Network.

A 'Carer portfolio holder' position was first established in the Department of Health in 2007. It has been filled by family/carers with lived experience and/or who have worked extensively with carers in the community sector.

Policy experience is required for the role.

Family/carer involvement in WA

As stated, the primary mechanism for family/carer involvement in WA mental health services is currently a 'carer representative' model. This is a service-specific, systemic advocacy work, in which family/carers are paid certain costs to sit on Committees, Boards, Advisory Bodies and similar to provide family/carer input. Funding is provided by the Mental Health Commission. Many of the carers who do this work are recruited by Carers WA, which administers a Mental Health Carer Representation Program to train, place and support carer representatives sitting on committees and advisory groups convened by state-funded mental health services.

The use of carer representatives expanded after the passage of the *Carers Recognition Act 2004* (WA). Under the Act, any person or body providing a service under contract with a WA government funded health or disability service is required to comply with the Western Australian Carers Charter. This states that the role of carers must be recognised by including carers in the assessment, planning, delivery and review of services that impact on them and the role of carers (Schedule 1(2)).

In 2010, the Southern Metropolitan Area Health Service's Peel and Rockingham/Kwinana (PaRK) Mental Health Services employed the first Carer Consultant in WA, to provide carer and family support and education input across PaRK's health service. The worker in this position has since resigned and at the time of writing, recruitment was being undertaken to fill the role.

Peer support and systemic advocacy work on the needs of mental health carers is carried out by ARAFMI, Carers WA, unfunded advocacy group Mentalhealthmatters2 and individual unpaid family/carers.

5. Literature review – Part II

Evidence base for peer work

The evidence base in the emergent peer work sector is limited. Primarily due to funding constraints, peer programs are often not reviewed and rarely evaluated. The literature on peer support is largely positive but mostly descriptive and further research is required (Orwin, 2008).

Consumer peer work

Most evaluations of peer work in mental health have studied consumer peer work, particularly peer support. There are both important differences and important similarities between the roles and experiences of consumer and family/carer peer workers and material that is useful in the development of the family/carer peer workforce can be drawn from the consumer literature. This information is not detailed here. Readers are directed to recent literature reviews into consumer peer support, listed in the references section (Doughty and Tse, 2005; Hinton, 2009; McDonald, 2010; Repper and Carter, 2010; Repper and Carter, 2011) and current Australian projects such as the Peer Work Project in South Australia, the NSW Consumer Advisory Group (CAG) Consumer Workers' Forum project and Victoria's Centre of Excellence in Peer Support (Mental Health).

Briefly, Repper and Carter (2011) found the literature demonstrates that receiving support from peer support workers (PSWs) can lead to a reduction in admissions for consumer. Noting that the evidence is limited, they conclude,

> *Although scarce in the literature, the few experimental trials show that at the very least, PSWs do not make any difference to mental health outcomes of people using services. When a broader range of studies are taken into account, the benefits of PSW become more apparent. What PSWs appear to be able to do more successfully than professionally qualified staff is promote hope and belief in the possibility of recovery; empowerment and increased self-esteem, self-efficacy and self-management of difficulties and social inclusion, engagement and increased social networks* (p.400)*.*

Doughty and Tse (2011) studied consumer-led services and concluded, "Overall consumer-led services reported equally positive outcomes for their clients as traditional services, particularly for practical outcomes such as employment or living arrangements, and in reducing hospitalisations and thus the cost of services" (p.252).

Family/carer peer work

One-to-one peer support

Several recent Australian studies have investigated the impact of one to one peer support for family/carers of people with a mental illness. Foster (2011) evaluated a pilot emotional support service offered to carers in rural Queensland. The carers were participating in Mental Illness Fellowship's Well Ways psychoeducation program and were offered additional, one to one support provide by a family/carer who was also a qualified allied health professional. The qualitative evaluation found it enhanced the carers' capacity to manage their own wellbeing as well as their caring roles. Three themes emerged: dealing with difficult times, connecting through shared experience and exploring different options. Carers sought emotional support to deal with unresolved feelings including grief, anger, upset, frustration, lack of recognition and lack of people to turn to for

support, because the experience of caring was not well understood. It found that feeling understood, accepted and not judged by the carer worker were the most important factors in satisfaction with the service.

> *"What I find so easy to talk to (her) is, she's also living the same experience, and that is what makes it so much easier … it's almost like a different language, because you can't talk to a person down the street … I mean it's much easier to talk about it with someone else in a like situation." (Carer)*

> *"She shared her personal stuff as well with me, made it easier, because you feel like you're not talking to someone who thinks they're higher than you, or better than you, or more educated, or qualified, or anything else than you, so you're talking to someone who's gone through her own hell as well. So they don't sit there high and mighty ... and place their judgements as they do, so I think that's probably a huge part that she actually shares herself." (Carer)* (p.59)

Foster (2011) concludes,

> *A striking finding was that the most important factor in the success of the emotional support appeared to be the support worker's shared lived experience of being a family carer. This and the support worker's informal and accessible personal approach seemed largely responsible for participants' willingness to accept the support when it was offered to them. Notwithstanding the effectiveness of traditional models of psychoeducation and family support offered by health professionals (Doornbos, 2001; LeGacy, 1998; Reid et al., 2005), the findings of this study suggest that an important, additional, therapeutic factor for the family carer is the shared experiential understanding and empathy between them and a worker who is also a family carer. This has implications for the provision of future support services by carer and other organisations, as the participants in this study indicated they were much less likely to access or accept support from a health professional than a fellow family carer* (p.61).

Reflecting this, the impact of stigma around mental illness on family/carers as well as consumers is recognised in *Mental Health 2020* (Mental Health Commission, Government of Western Australia, 2011).

> *People experiencing initial or recurring signs of poor mental health, their families and carers often feel shame, stigma and fear of rejection, and as a result, do not seek help. Others, including colleagues, friends and other family members may not be sufficiently informed or confident to provide advice or support, or to help people access the right services. "Stigma leads to increased isolation with many carers feeling silence is better than reactions from admitting they care for someone with a mental illness."* (p.22)

Geraghty et al. (2011) studied the ways in which family/carers utilised a peer support service for parents of children admitted to a specialist mental health unit in Queensland. Four broad themes emerged in the content of the sessions: (1) parents' experience of the service (2) parents' emotional responses to their child's admission (3) coping with challenges associated with the admission and (4) parents' needs for information. It noted that the service enabled parents to voice their concerns to the Consumer Consultants (as they were termed) without fear of alienating the clinical staff upon who they and their children depended. Other factors included that they themselves had lived experience, there was greater power equivalence, that their primary role was to support the parents

(rather than the children) and they had relative freedom from the time constraints of a busy ward (p.259).

An evaluation of a Victorian family/carer peer support program (Eastern Health and Monash University, 2009) found that 94% of family/carers who had used the service rated the program as 4/5 or higher for helpfulness. Other results from the carer survey included:

- 75% had identified positive changes in themselves since using the service
- 75% most liked having the opportunity to talk to someone about life as a carer
- 63% found the links to information and other resources helpful
- 25% would have liked a follow-up discussion, 38% identified they needed more time during consultations and 25% wanted a greater range of staffed hours
- 100% would recommend the service to others

Areas for improvement included increasing staff understanding and utilisation of the program and increasing service hours.

In 2006, Central Northern Adelaide Health Service (CNAHS) employed (consumer) Peer Specialists and Carer Consultants in five acute units and several statewide specialist services. (Note that although they are termed consultants, these roles provided peer support.) A study investigated the impact of the peer support service on the consumers and carers who used it and any perceptual shifts among both the pre-existing service staff and the newly employed consumer and carer workers after six months (Kling et al., 2008). Carers' responses about their contact with the Carer Consultants were positive overall. The highest ratings indicated that Carer Consultants were considered "better than good" at helping carers feel supported and reducing carer distress by sharing their coping strategies. The dominant theme in comments provided was that the Carer Consultants' personal experience provided them with a knowledge and insight that that helped carers feel more comfortable and supported. One carer stated, "After 10 years, it was the first time I ever felt a connection." All suggestions provided for improving the service were about increasing availability through ongoing follow-up after discharge, providing a country service, employing more Carer Consultants and making their positions full-time.

Interestingly, the perceptions of pre-existing staff of the consumer and carer consultant roles had declined when compared to their attitudes reported before the roles commenced. This indicated less favourable perceptions over time. Average reported scores remained in the positive response domain. Difficulties which were reported by both the consumer and carer peer workers and other staff included:

- Role clarity
- Communication
- Need for an improved referral system

Difficulties reported by the consumer and carer workers included:

- Fitting in with pre-existing team dynamics
- Unexpected pressures of working in an acute environment

Difficulties reported by pre-existing staff included:

- Selection, training and management of additional staff
- Knowledge and skill gaps (training needs)

Positive comments by pre-existing staff were also provided. In contrast, the Peer Specialists and Carer Consultants perceived their roles *more* favourably over time.

The authors suggest other possible reasons for the decline in pre-existing staff's perceptions, including the surprisingly high pre-assessment scores by pre-existing staff and the level of systemic and cultural adjustment required. They note informal qualitative reports from similar interstate roles that the "initial 12-18 month timeframe is a period of augmenting role clarity and embedding systemic change" (p.94).

A review of the Victorian Carer Consultant program found that Carer Consultants can play a role in averting, reducing and resolving existing and potential conflict between services and carers (Victorian Department of Human Services, 2008).

Internationally, US studies in Kansas, New York, Alaska and Michigan found the use of Parent Support Providers for parents of children with a range of issues including mental health, substance use, intellectual disability, learning disorders, autism spectrum and physical disabilities provided the following outcomes:

- Decreases the number of missed appointments to clinics
- Increases attendance in school and graduation rate for children
- Decreases the use of 'high end care' and long-term residential placement
- Increases the parent's self-assessment of 'practical knowledge' about resources and 'care coordination'
- Decreases the parent's stress level about parenting

(Purdy, 2011)

Also in the USA, Hoagwood et al. (2009) carried out a comprehensive review of family support programs in children's mental health and found that due to their lived experience, peer family advisors often have credibility with services, engender a sense of trust and can therefore assist in parents becoming more actively engaged in the services their child is using. They also found peer family advisors provided parents with affirmation and understanding.

Support groups

As stated, most research into the effectiveness of peer support has investigated peer support groups. A previous literature review carried out by ARAFEMI Victoria (Bartolo and Sanders, 2008) looked at the outcomes of participating in support groups for a broad range of carers:

- Parents and caregivers of young children and teenagers
- Carers of aged persons
- Carers of people with an intellectual disability
- Carers of people with a physical illness
- Carers of people with a mental illness

It is noted that peer support can also be gained through informal networks, however this review focuses on more formalised groups. A detailed overview of empirical findings and corresponding publications can be found in Bartolo and Sanders (2008); they are summarised here.

The literature indicates that peer support assists carers to manage and continue in their caring role. For example, Smith and Tobin (1993) surveyed 235 carer-parents. They found development of peer support groups among the five essential service initiatives for older parents who care for a developmentally disabled adult-child. Zimmer (1982) found carers of elderly persons sought information, skills training and mutual support from community-based carer groups. Borden (1991) explored the experiences of 51 care-giving spouses of older adults with chronic dementia and results showed coping strategies and peer support predicted carer wellbeing. In 2005 Kurz, Hallauer, Jansen and Diehl reviewed literature about carers of people with dementia. They concluded that peer-led self-help groups have the potential to improve the carer's emotional support, increase social contact, strengthen control over one's life and thus facilitate care-giving, lessening psychological burden. Kurz et al. (2005) found professional assistance for carers, and not peer support group attendance, reduced hospital admissions for the person with dementia. (It is also possible that carers attending support groups gain information, education and better access to services and professionals, which may indirectly contribute the consumer's recovery.)

For carers of people with mental illness, O'Grady (2004) found self-help groups may promote coping with stigma among families caring for a relative with a mental illness. According to a study by Knudson and Coyle (2002) there is a lack of support from social networks for carers of people with schizophrenia. Both informational and emotional support are available through self-help groups. Ferriter and Huband (2003) found self-help groups, family and police are more helpful than professionals in the mental health field. Based on the experiences of 124 carers of persons with mental illness, Provencher, Perreault, St-Onge and Rousseau (2003) concluded that diverse networks, including other carers and those who are not carers, are of maximum benefit. Also the quality and not quantity of exchanges are of most importance to carers.

Peer support groups can fulfil a range of functions. A paper by Munn-Giddings and McVicar (2007) presents findings from a doctoral study with two self-help/mutual aid groups for carers in England. Interviews with 15 active members explored reasons for joining, benefits derived from membership, and perceived differences between support gained by membership and their relationship with professionals.

> *Most group members had prior experience of voluntary work/activity, which influenced their decision to join, often prompted by a failure of the 'usual' support network of family/friends to cope or adjust to the carer's needs. Members reported personal gains of empathy, emotional information, experiential knowledge and practical information, based on a core value of reciprocity through peer support. It is this latter benefit that sets apart membership of self-help groups from groups supported by professionals who may not appreciate the scope and breadth of carers' responsibilities, or of the importance of their relationship with the person for whom they care. In this way, self-help groups offered additional, but not alternative, 'space' that enabled members to transcend their traditional role as a 'carer'. It is concluded that self-help/mutual aid groups, based on reciprocal peer support, offer a valuable type of resource in the community that is not replicable in professional-client relations* (Munn-Giddings and McVicar, 2007 p.26).

Benefits carers obtained by participating in peer support programs included more knowledge about the illness, more confidence, reduced caregiver burden, better management of difficult feelings, better family relationships, increased contact with family/friends and improved physical health in the long-term.

An important finding of research is that benefits stretch beyond the carer to include benefits for the consumer. For example, Heller and Cadwell (2006) carried out a study with ageing carers of people

with developmental disabilities. The program included five small group workshops and a legal/financial training session. In addition to program benefits for the carer, Heller and Cadwell found an increase in daily choices of the individual with a disability.

Empirical research represents an even spread of effective programs co-led by professionals or solely peer-led. Generally this component makes little difference to the impact of the program on participants.

Findings indicate that effective models include two key aspects of peer support, those of learning and support. Support can encompass informal sharing of stories or a structured psycho-education program about ways of coping and facilitated problem solving. Learning and information sharing can encompass both informal networking and resourcing and structured education programs or information sessions.

The evidence suggests that peer support without an explicit education-focus can work well for carers, perhaps because informal learning between members can still take place. For example see Winter and Glitin's (2007) telephone support group model for carers of people with Alzheimer's or Henrikson and Andershed's (2007) support group program for informal palliative carers. However, psycho-education without a focus on peer support may be less effective, as suggested by Chien, Chan and Thompson (2006). They found families who cared for a relative with mental illness attending a support group showed greater improvement in family functioning and less carer burden than participants who attended family group workshops regarding coping strategies.

Adding a third component to learning and support, services like home-visiting or counselling, adds another level of support to a peer support program. However, whether these additions provide additional benefits to peer support alone was unclear in this review. Mittelman, Roth, Clay and Heley (2007) developed a program for spouse-carers of people with Alzheimer's disease. It included six sessions of individual/family counselling, a support group and long-term ad hoc telephone support. They found that spouses who attended the (learning, support and services) program reported improved health two years later. An additional service component was also added to Mohide, Pringle, Streiner, Gilbert et al. (1990).

Chien et al. (2006) conducted a randomised control trial examining the effects of participating in a mutual support group for Chinese families of people with schizophrenia in Hong Kong, compared with families who were offered psychoeducation or standard care only. Participation in the mutual support group resulted in "substantial positive effects over the 18 months following the intervention."

> In comparison with psychoeducation and standard care, the results indicated significant and consistent improvements in the family burden of care in terms of finance, daily life and activities, interaction with the patient, mental health, and all aspects of patient functioning, including self-maintenance, interpersonal functioning and community living skills.

The mutual support group was embedded in routine out-patient care.

Support groups for young carers

Hargreaves et al. (2005) evaluated Paying Attention to Self (PATS), a program for young people with a parent affected by a mental illness. Its core focus is peer support groups, which are co-facilitated by a young person with a parent affected by a mental illness and a health professional. They found participants reported significant reductions in depressive symptoms (60% pre-intervention, 38% 12

months later), risk of homelessness (44% pre-intervention, 17% 12 months later) and stigma (30% pre-intervention, 15% 12 months later) after their involvement in the program. Participants reported that PATS had assisted them to:

- Learn more about their parent's mental illness, thereby enabling them to recognise symptoms and not to be scared
- Realise they were not alone – other young people were having similar experiences
- Have increased confidence in seeking help
- Understand better their parent's experience and to empathise
- Not blame themselves
- Cope better – through better communication, valuing self, staying calm
- Accept and to deal with feelings
- Have fun
  (Hargreaves et al. 2005 pp.84-85)

In 2008, Carers Association Victoria evaluated their 'Lulus' model, developed from a pilot peer support program for young carers. They found that the greatest benefit of peer support groups for the participants was in reducing the isolation young carers experienced because of their caring responsibilities. Providing young carers with the opportunity to explore and discuss their feelings, often for the first time, and talk about coping strategies was clearly beneficial (Carers Association Victoria, 2008).

Individual advocacy

In a 2007 study exploring carer needs and service responses in Victoria, family/carers identified the need for individual advocacy, broader systemic advocacy and carer needs for flexible and timely support in both of these areas (Sanders, 2007). The concept that people may need someone to walk beside them at times when they were not able to both care and fight was often raised. In discussing ways that ARAFEMI could better respond at an individual level, the notion of a Carer Advocate was raised. The aims of the role were to provide assistance to family/carers, orientate them to the services available, provide encouragement to explore the most effective treatment options, support them in having their voice heard and give specific advice in relation to rights and advocacy (Sanders, 2007). One family/carer described this need as follows:

> *There are times when I want to and can go and fight the system … and there are others when I want someone with expert assistance to come and help me* (Sanders, 2007, p.34).

An evaluation of the Victorian Carer Advocate pilot project was completed in 2011. It found that carers reported a high level of satisfaction with the service (ARAFEMI, 2011). They spoke about feeling heard, understood and respected and considered the contact had been useful to them.

The Carer Advocate reflected as follows:

> *After 18 months in the position I am proud of what the Advocate role has been able to achieve for carers. Many carers feel disempowered by the mental health system and other intersecting systems such as the legal system. In my role as Carer Advocate, I have been able to mitigate the power differential that exists within the various systems in a myriad of ways. For example, sitting with a carer at a family meeting held at an area mental health service can dramatically alter the dynamics of the meeting and enhance the communication process to bring about more desirable outcomes for the carer involved. From my experience and the feedback I have received from carers, the family meetings that I have attended are more*

respectful of carers, collaborative, and productive. This results in positive modeling for services of how to hold family meetings that have positive outcomes for all involved.

Intervening at the local level with the relevant players as an objective, service-neutral, independent participant will often assist to reduce the anxiety levels of all concerned and help to decelerate the intensity of the situation at hand. At the micro level this ultimately saves the area mental health service involved copious amounts of time that may have been spent trying to 'patch up' the damage that has occurred. At the macro level these types of interventions will ultimately assist area mental health services to more effectively collaborate with carers and increase their participation which can only improve services that are provided state-wide to consumers and carers alike (p.45).

Service providers also had positive feedback about the service. They reported it had been of benefit having the Carer Advocate involved and some services later went on to refer other carers or seek the involvement of the Carer Advocate when complex issues arose.

Systemic advocacy

Employing consumer and carer peer workers in mental health services enables them to contribute to service development. In her study of consumer peer workers, Bennetts (2009) states, "consumer perspective improves the culture, quality, effectiveness and responsiveness of community mental health services (p.33)." Employing consumer workers also enhances the visibility of the consumer voice at individual treatment and service delivery level to inform cultural and structural change in service delivery and workforce development (Dixon, Krauss and Lehman, 1994 cited in McDonald, 2010). Employing carer peer workers provides similar opportunities for carers to contribute to service improvement.

Employing peer workers is also linked to a recovery orientation in services. A recovery orientation:

- Focuses on people rather than services
- Monitors outcomes rather than performance
- Emphases strengths rather than dysfunction
- Educates people who provide services and the public to combat stigma
- Fosters collaboration as an alternative to coercion
- Promotes autonomy and decreases reliance on professionals

(Mental Health Coalition of SA brochure, 'What is Recovery?' cited in BaptistCare and MIFSA, 2009, p.5)

Employing family/carers with lived experience also provides a means for family/carer participation in planning, delivery and evaluation of services as policy commitments require. The employment of consumer and later family/carer workers with lived experience was originally based partly on the right of those stakeholders to have a say in the services they use and which have central impact on their lives (Stewart, Watson, Montague and Stevenson, 2008 cited in McDonald, 2010).

Peer work and culture change

> *"Consumers have said that staff treat them differently when I'm there. They see me as a bit of a policeman I suspect." (Peer worker)*
>
> *"It changes the atmosphere." (Colleague)*
>
> *"He's changed the way we do things. Generally staff views have moved and people talk about clients more politely. There's been a lot of a cultural shift. Low performing staff have been pulled up … he's like another check and balance … and he gives good constructive criticism." (Manager)*

Culture change is described as follows,

> *Culture change differs from other types of organisational change. The shared beliefs, values, and behaviours of organisational members become the target of the change process rather than solely focusing on the structures and systems within which people work.*
>
> (Waterhouse and Lewis, 2004 cited in Southern Health, 2010, p.10)

The Mental Health Council of Australia's 2005 report *Not for Service* found that the attitudes and practices of mental health professionals significantly impact on consumers' and family/carers' experience of services.

> *Accounts of highly negative, dismissive or stigmatising remarks by health staff towards persons with mental illness are still too common. Additionally, family members often feel discounted or ignored by health workers, even though they are expected to contribute greatly to ongoing care. Thus, while some attention has been directed to this issue in the past, it seems that there is little evidence now of a systematic response to inappropriate behaviour by mental health professionals.*

The Victorian Department of Human Services (2008) found that arrangements which supported good outcomes for Carer Consultants included a mandate to 'change the culture' through formal messages and structures. Examples of culture change occurring through employing consumer peer workers are contained in an evaluation of the South Australian Peer Work Project (Biedrzycki, 2008), as illustrated by the following quotes:

The presence and voice of peer workers can increase the understanding and valuing of the knowledge gained through 'lived experience' as well as clinical expertise. As stated in the Western Australian *Mental Health Towards 2020* consultations,

… Staff need to be invested in to encourage the move away from a medical model where mental health practitioners assume 'expert' status … [Practitioners] need formal training in how to partner with people.

(Mental Health Commission, Government of Western Australia, 2010)

Working alongside consumers and family/carers as colleagues and experiencing them as competent and outside of a service provider/recipient relationship can assist in shifting professionals' attitudes.

The external evaluation of the Victorian quality improvement initiative *Mental Health Experience Co-Design* (MH ECO) found that having consumers and family/carers working alongside mental health service staff improved each stakeholder's understanding of the others' experiences (Goodrick and Bhagwandas, 2011, unpublished). In turn, this impacted positively on the relationships between staff, consumers and family/carers more widely, that is, beyond the project participants. The evaluation found,

Staff identified that participating in the process of Co-Design with consumers and carers shifted their perceptions and attitudes about the potential scope of participation, and informed better ways to engage consumers and carers in service improvement (p. 4).

However, the South Australian Peer Work Project evaluation makes it clear that there cannot be an expectation that peer workers 'enact culture change' alone.

"The culture needs to support peer work and then other staff would follow. As a single peer worker you're not going to be able to change the culture."

(Peer worker, in Franke et al., 2010, p.183)

"It's too much of a personal burden to feel like you're banging your head against a brick wall. Trying to get acceptance is too hard without support." (Peer worker)

Similarly, Stamou (2010) found that in the UK,

Often employing organisations anticipated that employing a single worker could solve complex issues of user involvement.

It is clear that this task cannot fall to peer workers alone; work to improve the culture of mental health services needs to occur on many levels.

Content of various carer peer roles

The roles carried out by peer workers are "diverse and expanding" (Cleary et al., 2006) and are now far more sophisticated than when originally introduced (McDonald, 2010). Family/carer peer workers around Australia now perform a range of tasks under an array of different titles including:

- Family / Carer Workers
- Family / Carer Peer Workers
- Family / Carer Peer Support Workers
- Family / Carer Consultants
- Family / Carer Advocates
- Family / Carer Advisors

- Family / Carer Coordinator
- Coordinator of Family / Carer Participation
- Family / Carer Liaison Officer
- Family / Carer Trainers or Educators
- Family / Carer researchers

Rather than focussing on titles, this section describes the tasks commonly carried out by family/carer peer workers. Example position descriptions for family/carer peer roles, including responsibilities and essential and desirable criteria, are contained in Appendix A.

Peer support

Peer support workers work directly with families/carers to provide support. Mead (2003) describes peer support as follows:

> *Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful … It is about understanding another's situation empathetically through the shared experience of emotional and psychological pain.*

One-to-one peer support can include one-off sessions and more intensive, ongoing support. Peer support workers may also facilitate groups. Peer support is a "specific and very skilled job." Tasks typically carried out by peer support workers include the following:

- Providing carers with **information,** eg.
    - Assistance with navigating the mental health service system
    - Assistance to understand all options available and make informed decisions
    - Rights as a family/carer
    - Supports and options available

- **Education** and skills development, eg.
    - Communication
    - Problem-solving
    - Crisis management
    - Coping skills
    - Self-care
    (Hoagwood 2009)

- **Practical support,** eg.
    - Assistance with filling out paperwork (which may particularly required by CALD carers)
    - Transport
    - Access to brokerage money such as crisis funds

- Providing **emotional support,** eg.
    - Listening empathetically, as someone who may have had similar experiences
    - A chance and space for carers to focus on their own emotions and needs (Caring Together Evaluation, p14)
    - Designed to reduce isolation, decrease stigma, guilt, shame, helplessness

- **Liaising** between mental health professionals and family/carers

- Averting or reducing conflict between services and family/carers; promoting productive relationships
- Providing feedback to the service about family/carers' experiences of the service and their needs

- Providing **linkage and referral** to other community supports and services as required, eg.
  - Respite
  - Support groups
  - Family/carer organisations
  - Other NGOs

Individual advocacy

Carer Advocates carry out independent casework advocacy, assisting family/carers to resolve issues they have been unable to on their own. This can include:

- Attending family meetings with families/carers
- Facilitating improved communication between family/carers and relevant services
- Assisting carers with letters of complaint.
- Attending reviews hearings of involuntary treatment orders with family/carers
- Advocating with other services families/carers interact with, for example Centrelink, the criminal justice system, State/Public Trustees
- Providing information about carers' rights and entitlements, for example under legislation
- Supporting carers to ask questions and self-advocate with professionals whenever possible

Ideally, the model used is a non-adversarial, conflict resolution framework which seeks a solution agreeable to the consumer, carer and service staff.

Systemic advocacy

Family/carer workers work with staff of mental health services to improve service responsiveness to families/carers (Victorian Department of Human Services, 2008). For example, this can be done by:

- Sitting on service committees and attending meetings to provide a family/carer perspective
- Providing training to staff on family/carers' experiences and needs
- Providing secondary consultation to staff
- Consulting with other families/carers and feeding their views back to the service
- Having input into policy, strategic planning and service development
- Creating family/carer-friendly resources such as information sheets, information packs and newsletters
- Participating in accreditation processes

Policy development / advice

Family/carer workers employed within government provide advice on mental health policy and other issues relevant to families/carers.

The types of work carried out include the following:

- Reviewing Departmental policy from a carer perspective

- Providing consultation for Departmental staff on family/carer issues
- Liaising with mental health services about the implementation of mental health policy relating to family/carers
- Acting as a liaison between family/carers, family/carer organisations and government
- Facilitating meetings and connections between family/carers, family/carer organisations and government
- Managing the Department's contracts with family/carer organisations
- Advising family/carers and family/carer organisations on government processes and procedures
- Promoting family/carer initiatives within the Department

Skills required

When peer positions were first introduced, the only criteria under which consumers were employed was lived experience (McDonald, 2010). It is increasingly recognised that for the positions to effectively fulfil the purposes for which they were designed, relevant skills are also required. These vary according to the role and tasks performed and it is recommended that services recruit accordingly.

Consumer and carer peer workers also need to be able to draw on both their personal experiences and a wider body of knowledge (see, for example, Bennetts, 2009). For family/carer workers, this includes knowledge about issues family/carers commonly experience and an understanding of the service systems which impact on them.

In the evaluation of the Victorian Carer Advocate program (ARAFEMI, 2011), the Advocate's Manager reflected on the skills and qualities required of the Carer Advocate as follows:

> *Many personal qualities are required of the Carer Advocate including patience, a clear head, independence, existing skills, in terms of understanding the system, and assessment skills (how to define the problem with the carer, how to identify what would assist the carer, how not to take over from the carer, and how to know when to directly intervene with the system.) The Carer Advocate must have an awareness of an 'intervention continuum', from the simple conversation with the carer, who is able to act on their own part, through to mediation with the system, through to full formal advocacy with a focus on the concerns of the carer.* (p.44)

Further discussion of barriers and enablers for the successful implementation of peer work programs can be found in the 'Issues faced' and 'Ingredient for success' sections below.

Models of peer work used

'Models' of peer work can refer to theoretical or structural models. Models can defy easy categorisation and views on the best models are divided.

Theoretical models

Consumer peer support can be considered to belong to different theoretical models based on whether or not it assumes a medical model of mental illness (Orwin, 2008). Family/carer peer

supports have been posited as sitting between the biomedical and psychological models (Bartolo and Sanders, 2008).

Structural models

Currently, a 'key dilemma in the debate' (Hinton, 2009) in Australia is whether peer workers are more effective when they are employed by clinical services or non-government organisations. Challenges which have arisen in the employment of peer workers in traditional mental health services are detailed in the following section, 'Issues faced.' In terms of models, Bennetts (2009) observes that "consumer workers are often employed within services that neither necessarily share similar goals or values with the consumer workforce, nor cater well for its recourses, supervision or training requirements." (p.15) Having peer workers employed by consumer or family/carer organisations can make it easier for peer workers to retain their identity, as well as providing a measure of independence of the service. This may mean consumers or family/carers who are unhappy with the service are more likely to access the support.

However Hinton's research into Australian consumer peer workers (2009) found that "many informants saw the advantages of both approaches and wanted to see models which combined the most positive aspects of working inside and outside traditional mental health services" (p.31).

A longitudinal, nonequivalent control group design study conducted by Felton et al. (1995) in the United States studied the employment of consumer peer specialists as part of an intensive case management program. It found that compared to control groups, clients served by teams with peer specialists demonstrated greater gains in several areas of quality of life and overall reduction in the number of major life problems experienced. They also reported more frequent contact with their case managers and the largest gains of all three groups in the areas of self-image and outlook and social support.

In New Zealand and the United States, consumer-run organisations are more common and are frequently the employers of peer workers. Orwin's thematic review of peer supports in New Zealand (2008) stated,

> *Structural models of peer support in New Zealand often centre on the difference between so-called 'integrated' and 'independent' models. The former denotes peer support provided independently of traditional mental health services, usually by service user-run organisations, and the latter refers to peer support integrated within traditional District Health Board (DHB) or non-government organisation (NGO) clinical or non-clinical mental health services. There is some controversy over 'integrated' models of peer support within the service user movement and the literature, with claims that insensitive integration or collaboration with traditional DHB or NGO mental health service providers can compromise the integrity of peer support.* (p.3)

Consumer or family/carer-run organisations are less common in Australia.

Peer work models in specific populations

Peer support can also utilise different models in specific populations. Some specific issues and models of peer support are described below.

Aboriginal and Torres Strait Islander peoples

Work to develop and support the Aboriginal mental health workforce is being carried out to provide culturally appropriate and responsive mental health services and build the capacity of communities to respond to their mental health needs, particularly in the Northern Territory, Queensland and Western Australia. Remote and very remote areas of the Northern Territory and Western Australia have a high proportion of carers who are Indigenous (Edwards et al., 2009). Due to experiences of colonisation, dispossession and genocide, most Aboriginal people have experience of issues with social and emotional wellbeing and formal and informal supports for people and families can stem from that.

The Personal Mentors and Helpers (PHaMs) scheme has developed a remote servicing model. This has a strong (but not exclusive) focus on working with Indigenous Australians living with a mental illness in remote communities. The PHaMs remote service model differs to the mainstream service in its strong focus on spiritual, cultural, mental and physical healing for Indigenous Australians. The model incorporates more traditional cultural healing practices and utilises broader community activities to support healing. It aims to enable social inclusion and strengthening of family and community relationships, as well as the development of the community as a whole. This community development approach includes working with individuals and their community support networks and introducing cultural and family brokers to promote cultural competency (Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs website, accessed 5 October 2011).

A Community Peer and Mentor project involving Psychiatric Rehabilitation Australia and Pius X Aboriginal Corporation in NSW aims to support people with mental health issues including by providing support for people to stay connected to existing community relationships, establish positive new community relationships and for Psychiatric Rehabilitation Australia to support the Aboriginal Corporation to provide mental health services locally.

Rural, regional and remote communities

A 2009 Carers Australia report (Edwards et al., 2009) suggests that carers in outer regional and remote Australia experience a 'tyranny of distance,' including difficulties in accessing services, higher rates of disability for carers, younger age of carers in remote areas and the impact of drought. It states,

> *While the rural communities in which these carers live provide informal supports by way of information and advice, carers do seem to struggle to access services. The immediate task ahead is to insure unpaid family carers in rural and remote areas of Australia have better access to appropriate support and services* (p.34).

Similarly, Foster (2011) emphases the impacts on carers in areas where there are fewer mental health services and their consequently greater need for support:

> *… it needs to be recognized that in rural/regional/remote settings with very limited services, health professionals are often not able to devote significant amounts of time to supporting family carers in addition to their usually substantial client workloads. A lack of other health professionals such as counsellors and therapists in these settings adds to the need for emotional support services to be routinely offered in Australian rural/remote/regional areas by family carer/health professionals in conjunction with carer education programmes such as Well Ways* (p.61).

For family/carer peer workers in rural/regional/remote areas, specific issues which can be faced and need to be addressed in establishing programs include:

- It can be more difficult for the person they provide care to obtain mental health care from a different mental health service from the one they are employed by (for example, if there is only one)
- Dual relationships such as personal relationships with consumers and other family/carers are more likely
- Confidentiality can be a significant issue in small communities

Culturally and linguistically diverse communities

In Victoria, community agency Action on Disability in Ethnic Communities (ADEC) is funded to provide a mutual support and self help program targeting CALD carers. They run ethno-specific support groups, provide telephone support and information provision and carry out systemic advocacy work.

A New Zealand study which interviewed peer support participants from Maori, Pacific and Chinese communities found that peer support translates well across cultures. However models needs to be adapted according to the cultural needs of different groups and programs need sufficient operational independence to ensure the unique cultural aspects of the service are respected and preserved. Differences from mainstream peer support provision of course vary between cultures and between individuals within cultures, however they may include, for example, including the consumer's family in the peer relationship if the consumer desires this; supporting consumers who wish to participate in cultural activities or connect with others from their cultural background; participating in relevant cultural activities with consumers and taking on a wider role, for example in a consumer's social life (Orwin, 2008).

As stated above, Bo Ai She is a volunteer peer support organisation that supports Chinese mental health service users in New Zealand. In 2008, it had 90 service user members. It offers physical fitness and recreational activities; opportunities to share recovery experiences; educational workshops on general topics such as English classes; and workshops on recovery skills and techniques. Many members progress to become facilitators/trainers of the activities and leaders (board members) of the organisation. Evaluation work conducted in collaboration with Massey University and anecdotal evidence has found the group assists participants to become more socially active and adept, learn new skills to adapt to New Zealand culture, develop a sense of personal pride, independence and the ability to stand up for themselves as well as an apparent decrease in the number of hospital admissions (Te Pou, 2008).

The 'Caring Together' peer support project (ARAFEMI, 2010) was developed in response to an identified high level of acute readmissions for consumers from CALD backgrounds, including new and emerging communities. The model was designed to provide early and culturally sensitive support to family/carers at the inpatient unit or a community setting. The peer support worker was based at a specialist CALD community service to increase accessibility well as draw on the organisation's expertise. The peer support worker was also provided with extensive support and training in using interpreters and cultural sensitivity.

The STAR Centre (USA) has produced a useful, practical tool to assist peer-run programs and self-help groups to assess and enhance their services (NAMI STAR Center and the University of Illinois at Chicago, 2010). Evaluated in a national pilot test, it contains comprehensive resources, surveys, tips and concrete suggestions to support services to create and implement a Diversity Action Plan.

Retaining the integrity of peer support

When peer support workers are employed in traditional mental health services, Orwin (2008) identifies the following strategies to maintain the integrity of peer support.

Factor affecting integrity	Strategies to maintain integrity of peer support
Tokenism	Peer support team leader should be a peer Team leader should be a member of the senior management team Peer support should be operationally independent Funders should ensure there is peer leadership Funders should ensure the service is credible
Leadership	Explicit support for peer support from all levels of leadership Training of all managers, from chief executive to line managers, in peer support
Systems	Clear understanding of the role of peer support Peer support clearly differentiated from other support roles Policies and procedures adapted to support development of peer support workers
Supervision	Skilled, knowledgeable supervisors help peer support workers to 'stay peer' External supervision Active development of peer supervision capacity
Funders and outcomes	Understand that peer support is different from other forms of support Build mutual understanding between peer support service and funder Ensure outcomes consistent with the philosophy of the service Never demand clinical outcomes Accept that outcomes from peer support are evolving Look for qualitative measures that can capture the impact on lives Look for outcomes that are broader than just mental health outcomes

(Orwin, 2008. p.24)

Issues faced

Most of the literature on the peer workforce and issued faced in its development has focussed on consumer peer work. As many of the issues affect family/carer workers similarly, this section also draws on that body of knowledge and experience. Suggestions for addressing these issues and factors which have been found to assist in the successful establishment of peer programs are in the following section, 'Ingredients for success.'

An evaluation of the South Australian consumer Peer Work Project states, "The findings indicate that there have been many successful aspects regarding the integration of peer work across different types of settings, but that there are areas requiring significant improvement" (Biedrzycki, 2008, p.5). Similarly, research by Middleton et al. (2004) into the Consumer Consultant program in Victoria found,

> *Overall the findings of this research indicate that consumer consultants are having a positive influence in mental health services in Victoria. However, there are a number of limiting factors also at work. The key factors identified in this study reflect those already described from the literature. These include the stigma surrounding mental illness, the tokenistic nature of the job, the prevailing culture of the mental health service system and, at the organisational level, its resistance to change* (p.515).

Consumer consultants believe they have made real gains in providing effective representation of the consumer perspective, resulting in service improvement, but the results have been uneven, and many significant barriers persist (p.517).

Several studies and reports have investigated the significant barriers the peer workforce continues to face. The Consumer and Carer Relations Directorate at Southern Health states,

The underfunding and resourcing of consumer and family/carer participation across Victoria has resulted in many problems that have added to the difficulties in undertaking this work. Tokenism, poor definition (as well as misunderstanding) of role, the underestimation and undervaluation the contributions Consumer and Family/Carer workers can make to services is endemic.

(Southern Health, 2010, p.7)

The National Mental Health Consumer and Carer Forum details its concerns in a 2010 report:

For some time, the mental health consumer and carer identified workforce has reported:

• lack of clarity around job titles, roles and descriptions for these positions, often within services. This has a range of consequences including blending and overlap of consumer and carer advocacy and peer support roles and differing expectations about operations by consumer and carer identified workers, mental health service staff and mental health service management leading to confusion, stress and conflict;
• lack of supports to ensure that consumer and carer identified workers can carry out their job effectively, including but not limited to:
- shared understanding between consumer or carer workers and management and other staff about the principles of recovery;
- respect for or knowledge of the aims of the consumer or carer identified positions from other workers and a willingness to engage with them;
- clarity around potential conflicting lines of accountability – e.g. consumer and carer identified positions, depending on their role, can be accountable to both their employer and service users;
• discrimination (one of the most overt manifestations of stigma in the workplace) against consumer and carer workers stemming from a result of lack of knowledge and/or acceptance amongst co-workers;
• the relationship between consumer and carer identified workers and consumer and carer clients of services being dominated by mistrust; workers walk a fine line arbitrating between the sometimes conflicting approaches of mental health service culture and consumers and carers seeking to find and assert their power in their own recovery;
• deterioration of the relationship between consumer and carer identified workers and their employers where, employed as system advocates, consumer and carer identified workers are trying to initiate change while at the same time balancing the need to please their employer or fulfil the role of model employee;
• lack of award structure and clarity around pay rates resulting in inequitable rates of pay, not always based on identified skill levels or service needs;
• lack of minimum training requirements or on the job training.

Culture, stigma and attitudinal barriers

Attitudinal barriers can include a lack of value being attributed to the roles. The culture of mental health services is consistently reported as challenging for peer workers. The negative attitudes some clinicians hold towards consumer workers can limit the effectiveness of the roles (McCann, Baird, Clark and Lu, 2006 cited in McDonald, 2010). Both consumers and service providers consistently report workplace cultures in which stigma is the norm and discrimination and abuse are tolerated (McDonald, 2010). Studies have also documented the negative perceptions some clinicians hold of family/carers, who may be seen as causing or at least not managing their family member's mental health issues (see, for example, McAuliffe at al., 2009).

The generally part-time, low paid and low status nature of peer work can in turn contribute to the stigma and the undervaluing and undermining of the roles. Peer work can be perceived as volunteer work, or work which is less skilful or professional than other mental health work. This has also impacted by the lack of adequate training for peer workers, which is intended to be addressed through the development of the Certificate IV in Mental Health Peer Workers.

These issues have meant there is often a belief among consumer workers that there is a degree of tokenism in their employment, where participation is seen as a bureaucratic requirement generated by 'political correctness' (Nestor and Galletly, 2008). Tokenism is defined as "the inclusion of representatives from a socially marginalised group into a mainstream body in an expedient way which serves the purposes of the dominant group" (Epstein and Olsen, 1998 cited in Middleton et al., 2004, p.510).

Services' concerns

From the perspective of the services employing peer workers, the evaluation of the South Australian Peer Work Project (Biedrzycki, 2008) documents three major concerns of services identified by Carlson et al. (2001), which paralleled their experiences. These are:

- Dual relationships
- Role conflict
- Confidentiality

For consumer workers, dual relationships can arise if they are or have been a client of the mental health service they work for (for family/carer workers, the issue can arise if the person they provide care to uses or has used the mental health service they are employed by.) Dual relationships can also arise where peer workers have friendships with consumers or carers using the service.

For carer workers, this can be dealt with by ensuring the person they provide care to obtains care from another mental health service (if possible), ensuring supervision is carried out by staff where there is not a dual relationship, having clear policies and procedures, providing training and monitoring any issues in supervision.

Similarly, role conflict or confusion can arise where roles and expectations are not clearly defined. It can be difficult for consumer workers who must balance their consumer and provider identities (Salzer, 2002 cited in BaptistCare and MIFSA, 2009). Some staff may fear aspects of their roles being supplanted or the 'deprofessionalisation' of social work, for example. As there can be some overlap between peer work and other roles, teamwork is required (Cleary et al., 2006) to develop collaborative practices which complement rather than compete with or negate professional roles.

BaptistCare and MIFSA (2009) report that staff are sometimes concerned about breaches of consumers' confidentiality, for example where a peer workers know a consumer who is using a service. Again, this is best addressed by having appropriate policies, procedures, training and supervision in place.

Impacts of issues faced

The impacts of these issues have included stress (Bennetts, 2009) as well as conflict and other difficulties for peer workers (and other staff). The National Mental Health Consumer and Carer Forum (2010) describes these as follows,

> *Mental health consumer and carer identified positions are not yet consistently being supported at an appropriate level or with regard to best practice, strategic and tactical human resource management in Australia. This results in:*
> *• burnout for workers in consumer and carer identified positions;*
> *• lack of trust and respect between consumers, carers and clinical staff;*
> *• compromised health outcomes for mental health consumers and carers who utilise these services;*
> *• burnout for other staff of mental health services.*

This parallels experiences with consumer peer workers in the United Kingdom, where Stamou (2010) states that early in the employment of peer workers,

> *Burnout and stress were commonplace and the need for organised support and supervision of these employees became paramount.*

Some of these issues have arisen because of the ad hoc development of this emerging workforce. Services have employed consumers under variety of awards and conditions, with little consensus as to their roles and responsibilities. Consumer positions "evolved in an ad hoc fashion with an absence of guidelines or clarity about aims and functions and often minimal support and resourcing" (Hansen, 2003 cited in Hinton, 2009). Hinton (2009) states,

> *There has been a tendency to establish consumer positions as a 'good thing' in themselves without necessarily any rigorous analysis of the process, appropriate support structures and the impact of these positions* (p.49).

Stewart (2008) concludes, "Without clear job descriptions, common understandings of their roles, adequate preparation, ongoing support and access to supervision, we may well be setting consumer workers up to fail in a system that has already failed many of them."

The issues which have arisen highlight the work which needs to be done in order to see the successful establishment of peer work programs. The following section identified factors which support this.

'Ingredients for success'

The New Zealand *Service User Workforce Development Strategy* (Mental Health Commission, New Zealand, 2005) identified the following factors as crucial to the success of the service user workforce.

- Service user leadership
- Sector commitment

- A clear vision and strategy
- Effective management and co-ordination
- Adequate funding

In Australia, the National Mental Health Consumer and Carer Forum (2010) has made the following recommendations, based on the issues they have identified above:

Recommendations to support and develop the mental health consumer and carer identified workforce

1 Provide leadership in mental health workforce development and implementing the 4th National Mental Health Plan.
2 Identify the existing mental health consumer and carer workforce.
3 Implement change to support recovery oriented mental health services.
4 Support and develop the mental health consumer and carer identified workforce:
 4.1 Implement best practice human resource management and recovery;
 4.2 Minimise stress;
 4.3 Identify the job requirements and develop position statements;
 4.4 Assess parity of remuneration;
 4.5 Provide access to essential resources;
 4.6 Provide flexibility, support and reasonable adjustment;
 4.7 Implement effective performance management frameworks;
 4.8 Provide training and professional supervision;
 4.9 Address potential role conflict;
 4.10 Implement processes to support independence;
 4.11 Manage privacy and the disclosure of information;
 4.12 Develop leadership to support a healthy organisational culture and values.
5 Develop the future mental health consumer and carer identified workforce:
 5.1 Use the National Mental Health Consumer and Carer Identified Workforce Strategy to support excellence and innovation;
 5.2 Develop supported networks and strengthen leadership of the mental health consumer and carer identified workforce.

Key features discussed in the literature are highlighted below.

Organisational leadership and senior management support

Organisational leadership and the support of senior management is consistently identified as crucial for peer programs. Biedrzycki's evaluation of the BaptistCare and MIF SA Peer Work Project (2008) concluded,

> *Although there are many factors that influence the successful integration of peer work, the single most important determinant of success is very clearly whether or not there is genuine organisational leadership on the issue. This impacts on almost all factors influencing the integration of peer work, such as whether or not staff are accepting, and whether or not peer workers receive appropriate support in setting up and developing their role through what is potentially a very significant period of change both personally and for the workplace* (p.23).

Similarly, the Victorian Department of Human Services (2008) found,

Senior management have a critical role to driving and embedding understanding of the carer consultant role within the organisation. In the absence of this, carer consultants felt marginalised within the organisation and without access to the resources available to their professional peers.

Nestor and Galletly (2008) concluded, "A strong commitment by senior management is crucial" (p.345).

Organisational readiness and preparation

Middleton et al (2004) recommend that services considering employing peer workers assess their workplace culture to determine readiness and if it is not ready, to implement strategies *before* employing peer workers. They describe the elements of a 'collaborative and enabling' versus 'rigid and unresponsive' service and the impacts of service characteristics on peer work roles (see Appendix B).

The implementation model developed by BaptistCare and MIFSA (2009) describes a process of change management, including:

- Informing and educating current staff about the role of peer work. Clear role development and definition is important, to ensure clear communication of the role and function to staff
- Involving consumers, carers and relevant staff in the development of the position
- Listening to and addressing staff's concerns

Nestor and Galletly (2008) found that obstacles in introducing consumer peer support workers were generally more pronounced where there was little buy-in from staff. Where staff felt they had participated in the development of the service felt more positive about working with peer support workers. Orwin (2008) found that issues with professionals not supporting or accepting peer support workers were most intense early in their introduction. Factors that supported positive perceptions and relationships developing include:

- Seeing positive outcomes for consumers
- Education about the role of peer support
- The development of honest, reflective relationships
- Presentations and updates on the peer support program
- Building relationships between peer support workers and consumer advisors
- Open communication and dialogue, to help establish trust, respect and credibility
- A direct line of communication between managers of clinical and peer support staff

An evaluation of the Victorian COPES carer peer support program (Eastern Health and Monash University, 2009) found the biggest factor which would increase staff utilisation of the program was staff education. All of the eight peer support workers who had worked in the program identified problems associated with under-recognition of the peer support program by clinical staff and saw a need for greater staff education.

Clear and consistent job descriptions

It is noted that the wide range of titles used for essentially the same or similar types of work has resulted in confusion for peer workers, their clients, employing services, staff and other services with

which stakeholders interact. This is currently the situation in Australia. Consistency across roles (with some flexibility to tailor according to local needs) assists with clarity and understanding (Victorian Department of Human Services, 2008). It is crucial that job descriptions are clear and expectations agreed. It is also important the peer workers' place in an organisation's structure is appropriate and clearly communicated to other staff.

Significant difficulties have also arisen for peer workers when there is blurring of what are quite different roles, for example peer support and systemic advocacy. This can result in stress and conflict for the peer worker and employer as well as confusion for consumers or family/carers using the service. Several Area Mental Health Services in Victoria are now separating peer roles into two positions: peer support and systemic advocacy, in recognition that the roles are quite different and require different skill sets.

Consumer and family/carer workers have also highlighted that peer support and individual advocacy are different roles. It is increasingly recognised that it is not appropriate for peer workers employed in a service to carry out individual advocacy for consumers/carers using the service. At Southern Health in Victoria, there is explicit agreement that this is not done, as may affect Consultants' relationship with the service and the staff they are employed by. Consultants also need to work with the service in order to make other changes to improve service delivery to consumers and their families. Instead, consumers or family/carers requiring advocacy are supported and referred to independent agencies (Southern Health, 2010).

Number of workers employed and hours worked

Again, Stamou (2010) states that in the UK, "Often employing organisations anticipated that employing a single worker could solve complex issues of user involvement." A realistic assessment must be made as to the capacity of a single worker to create change and the pressure and cost to the worker due to isolation (Chinman et al., 2006 cited in Orwin, 2008, p.23). This is particularly so given the difficulties and barriers outlined above, and existing vulnerabilities that consumer and family/carer peer workers may have. Accordingly, consideration needs to be given to how many peer workers a service employ. One service user provider in New Zealand suggested four peer support workers is a desirable minimum for a service (Orwin, 2008).

Workers need to be employed for enough hours to fulfil role requirements, with realistic expectations and a feasible workload (Cleary et al., 2006). For family/carer peer support workers, this may include being available after hours to support family/carers who work during the day and visit consumers after work (for example, in inpatients units). The evaluation of the Victorian COPES family/carer peer support program found that both clients and peer support workers found the hours the service was available were insufficient (Eastern Health and Monash University, 2009). 34% of staff identified that increasing the hours of operation would increase their utilisation of the program. Consideration must also be given to the hours required to fulfil organisational requirements such as attending meetings and the need for peer workers to be at work often enough to become familiar with and integrated into the service.

Where appropriate, job-share arrangements can provide flexibility, team, peer support and enable workers to fill different roles according to their strengths. They can allow for access to part-time work, which may be preferred by family/carers with care responsibilities. However, a flexible approach is important to take into account individual preferences and needs.

Orientation and induction

The introduction of peer workers can be 'culture shock' for both peer workers and other staff (BaptistCare SA and MIFSA, 2009). Services and government departments need to ensure they provide a thorough orientation and induction, discuss and ensure an agreed understanding of the role and provide relevant information about the service, policies, procedures, processes and supports available.

Support

A survey of consumer peer workers carried out by the NSW Consumer Advisory Group (CAG) in 2010 found that formal support of peer workers was being provided in a wide range of ways including:

- Regular clinical supervision
- Support from the Employment Assistance Program
- Rehabilitation workers available on-call
- Support from Team Leader
- Peer supervision/support from other consumer workers at the service
- Independent counselling service
- Nursing Unit Manager
- An experienced consumer worker
- External peer supervision/support, for example monthly meetings
- Other mental health staff

Some workers reported having no formal support arrangements in place (McDonald, 2010).

As described above, employing a number of peer workers is one way to provide workers with access to peer support. Consumer and carer peer workers may also be able to provide support to one another. The Victorian Department of Human Services (2008) found that arrangements which support good outcomes for Carer Consultants included co-location with Consumer Consultants for resource sharing, team and peer support. This was also described as critical by a family/carer policy worker employed within government (Personal communication, 6 October 2011).

Another form of support which has been developed is networks of peer workers in different organisations. Orwin (2008) reports that peer support workers in New Zealand who had used local networks found them highly beneficial for networking and mutual support. In Victoria, the Victorian Mental Illness Awareness Council hosts monthly forums for consumer peer workers. Again, Carer Consultants have formed the Carer Consultant Network of Victoria (CCNV), a professional association.

For family/carer workers in government, supports can include regular meetings and liaison with a network of family/carers and family/carer organisations to reduce isolation and ensure regular communication and contact.

Supervision

The Victorian Department of Human Services (2008) found that Carer Consultants typically lack consistent supervision and that arrangements which supported good outcomes for Carer Consultants included strong line management and supervision. Similarly, the NSW CAG 2010 survey found consumer workers in NSW were receiving supervision from a wide of range of roles including:

- Nurse Unit Manager
- Manager of Planning and Performance

- Consumer Co-ordinator
- Rehabilitation Team
- Service Centre Manager
- Director of Mental Health Service
- Team Leader

Again, some consumer workers reported having no formal supervision structures put in place.

In New Zealand, Orwin (2008) found that "Indeed, effective supervision was identified by every participant in this review as the single most important element in successful peer support and one where capacity building is most needed" (p.26). The report describes different models of supervision used by various peer support providers. In the New Zealand context, the consultations found almost unanimous agreement that external supervision is ideal and can also support development of the role and maintain the integrity of peer support.

Appropriate boundaries for peer workers can be different to those of health professionals and can be ambiguous and uncertain at times. Accordingly, supervision to manage boundaries appropriately is important (including peer supervision), as well as training and professional development (Cleary et al., 2006). Recommendations have been made to develop a Code of Conduct and Guidelines for Practice for peer workers (Meehan et al., 2002 cited in Cleary et al., 2006) and NSW CAG has commenced work in this area in NSW.

BaptistCare and MIFSA's Peer Work Project offers consumer peer workers mentors or job coaches, sometimes external to the employing organisation. One peer worker commented,

> "Mentoring – it's about avoiding mistakes. Clients are so complex that mentors can help identify nuances of each client. (Line manager) can't help every day so mentors are vital."
> (Peer worker)
> (Biedrzycki, 2008, p.15)

Training and professional development

The review by the Victorian Department of Human Services (2008) found that Carer Consultants are typically provided with limited preparatory or ongoing training. Bennetts (2009) found that training and education for the consumer workforce is largely underdeveloped, with no standard training available and consequently wide variation in whether and what types of training is provided. Moll (2009) found that despite most consumer workers completing some form of training during their employment, many were put into situations they didn't feel ready for.

A lack of access to training and professional development opportunities available to clinical staff has been seen as a disparity which devalues peer work roles. Peer workers need ongoing training beyond recruitment (Lloyd and King, 2003 cited in NSW CAG, 2010) and have emphasised the importance of having career pathways. It is hoped that the development of the Certificate IV in Mental Health Peer Work and associated qualifications will improve the availability and consistency of training available to workers.

Career pathways

The lack of a career pathway has been identified as a barrier to job satisfaction and to the development of a skilled and sustainable peer workforce (Bennetts, 2009). This can assisted by

identifying opportunities for progression and increased responsibility, for example program management and the supervision of other workers.

Family/carer friendly workplaces

Employing family/carer peer workers requires recognition that a flexible workplace is important, particularly where a carer has ongoing care responsibilities. Carers' rights are increasingly covered under employment and anti-discrimination legislation. Relevant policies and procedures must be clear and accessible.

6. Consultations with key stakeholders

Method

Key stakeholder interviews were conducted to collect more detailed information on current Western Australian service frameworks and models, identified service gaps, sectoral readiness and capacity to assist in the design of evidence-based models for carer peer work services.

Interviews were held at the offices of ARAFMI WA or 'in situ' at the worksite of stakeholders. Interviews were conducted by the two research consultants. Consultations ran for approximately 1 to 2 hours.

The questions asked were as follows:

- Previous experiences of work done by people with lived experience as a family/carer (whether paid or unpaid)
- Current situation with regard to family/carer peer workers (paid or unpaid)
- Vision for the future
- Priorities in terms of funding
- Enablers and inhibitors in establishing family/carer peer work positions
- Whether family/carer workers need to have lived experience as a family/carer
- Thoughts about the terms of reference for this research – specific information on terminology and roles

All interviews were carried out in person, except one which was telephone only. Two follow up telephone interviews were carried out in addition to the in person interviews.

Interviews were recorded with the permission of participants. The two interviewers identified major themes and utilised post interview debriefing, notes and session recordings to compare data for cross-checking and reliability.

Consultations with the following stakeholders were carried out:

- Mike Seward, Executive Director, ARAFMI WA
- Liza McStravick, Manager of Counselling and Support Services, ARAFMI WA
- Kerry Hawkins, Carer Advocate, ARAFMI WA
- Paul Coates, CEO, Carers WA
- Donna Turner, Policy Officer, Carers WA
- Ronnie Burkin, Carer Representation Advisor, Carers WA
- Tara Ludlow, Manager - Advocacy and Policy, Carers WA
- Melissa Webb, former Carer Consultant, Peel and Rockingham Kwinana Mental Health Service
- Penny Thomas, Occupational Therapy Coordinator, Peel and Rockingham Kwinana Mental Health Service (telephone interview)
- Petra Elias, Head of Social Welfare Department, Graylands Hospital
- Jane O'Donnell, Community Development Officer, Swan Adult Mental Health Service
- Kathleen Smith, Acting Director for Nursing, Southern Metropolitan Health Service
- Fiona Cooper, Corporate and Projects Manager, Marian Centre

- Jane Gibson, Psychiatrist, Marian Centre
- Dr Rowan Davidson, Chief Psychiatrist, Department of Health
- Creswell Surrao, Clinical Consultant, Office of the Chief Psychiatrist
- Lesley Van Schoubroeck, Director – Organisational Reform, Mental Health Commission
- Sue Nye, Principal Project Manager, Mental Health Commission
- Pui San Whittaker, Principal Policy Officer, Mental Health Commission
- Family/carers and family/carer workers who attended a family/carer and non-government organisation forum

Results

Stakeholder views on the broad themes which emerged are presented below.

Family/carers' needs

The family/carers discussed their primary needs, including being respected and heard by mental health professionals; having the 24/7 nature of providing care understood; being able to access services for the person they provide care to; being able to access the information they require; being able to connect with family/carers who have been through similar experiences; financial support and emotional support to address a sense of hopelessness. The need for both practical and emotional support was highlighted.

These needs were reiterated across stakeholder groups, where there was high congruence and commonality in understanding of the impacts and consequences of caring. All stakeholder groups recognised the importance of carer involvement in mental health services, both on an individual level (in relation to the treatment and care of the person they support) and at a systemic level (having carers' voices represented in the planning, delivery and evaluation of services).

Titles and content of family/carer peer positions

All stakeholders saw a role for family/carer involvement in a range of capacities. There was broad support for the establishment of a range of family/carer peer positions.

A family/carer stated that the labels and titles given to various positions are critically important. It was noted many people in caring roles do not identify as 'carers' and prefer to be referred to simply as the mother, father, partner, brother, sister etc of the person they care for. It was also noted the term can be inappropriate in Aboriginal communities. However, the family/carer organisations also saw having some universality of language and a shared understanding and consistent application as important for the progression of carer peer roles in the workforce.

Peer support

The family/carers wanted to see the establishment of paid peer support workers to *"walk alongside"* families/carers and provide linkages and information. The value of having contact with others who had had similar experiences was noted, with a family/carer saying, *"It's different to have someone who's walked in your shoes, it's a really good feeling."* She spoke about how the school her child attended had (with her permission) given her contact details to another mother whose child was experiencing mental health difficulties. The mother was struggling to cope and when asked if she was aware of the supports available through family/carer organisations, said with relief, *"Yes, but it's so good to talk to someone who's been through something like me."* Another family/carer said, *"When a carer hears that the person they're talking to is a carer too, there's almost a physical*

reaction: it's very therapeutic. Carers' stories are often an untold, unheard narrative of violence, poverty and shame." Family/carers also saw this role as acting as a conduit between clinicians and families/carers.

The family/carer organisations described their experience of families/carers needing support in navigating the mental health system. They also expressed the view that peer support is valuable, describing it as a *"fantastic preventative and empowering role, which normalises carers' experiences."* However, they also noted their concern that family/carer peer support workers in clinical services do not simply duplicate services which were already being provided, such as support groups, which has occurred.

The Area Health Service stakeholders attributed value to peer support, for both consumers and families/carers. A desire was expressed for clearer definition of the roles and their functions, appropriate recruitment and training processes being further developed and greater oversight and monitoring provided. It was identified that appropriate supports need to be provided in terms of structure, sustainability, planning and appropriate funding.

Policy stakeholders (staff at Mental Health Commission and Office of the Chief Psychiatrist) also saw value in the provision of peer support to family/carers. The link between peer support and the recovery model was noted.

Individual advocacy

All stakeholders who commented on the Carer Advocate position at ARAFMI provided a positive response. The family/carers and family/carer organisations described it as an enormously important role. They talked about the value of being able to access a skilled, independent person who is not emotionally involved in a situation. They identified that the role had also promoted understanding among clinicians of family/carer needs and offered benefits to clinicians in terms of providing another support for the family/carer.

While discussing the role supportively, there was an additional caution from systems advisors at Mental Health Commission and sector workers to ensure that the role maintains clear definition and support to ensure clarity and manageability. This is so the role can retain a specific individual advocacy focus (in contrast to case management, for example, or systemic advocacy).

Some family/carers had been providing individual advocacy for one another on a voluntary basis. This included going to meetings with service providers. A family/carer described this work as follows,

> *I don't take over. I sit with them. If they forget to say something they've told me that I think is important, I remind them. If they want me to say it I will but the most important thing is teaching them how to do it themselves. I'm not their voice, I'm their support. I'm walking alongside them.*

She believed this work needs to be recognised and valued as paid work, saying,

> *We do it because we know what it feels like to hurt and be in pain and we have a need so we do it for one another.*

However she stated this was unsustainable and that family/carers doing this work on an informal, unpaid basis placed them in situations of unacceptable risk.

Systemic advocacy

As stated, all stakeholders acknowledged the importance of carer involvement in systemic advocacy work. The family/carers emphasised the funding of systemic advocacy work alongside support for individual carers. They supported the model of employing and embedding family/carer workers in services to do this work. Comments included,

> *"It's better (and cheaper) to put a fence at the top of the cliff than to have lots of ambulances running around at the bottom."*

> *"You don't want to see peer support workers giving carers emotional support without being able to do anything about the problems."*

> *"Many carers stop asking for help and just exist."*

Service providers and policy stakeholders also noted that family/carers would be accorded greater credibility and status by being in paid roles. This would enable them to be more effective.

Stakeholders discussed the *Carers Recognition Act 2004* (WA) and the Carers Advisory Council (CAC) set up under the Act. This was seen to have increased family/carer participation and given carers a greater voice: it has been a driver as institutions are required to comply. However both service providers and policy stakeholders noted that there are not large numbers of carers in these roles. The families/carers also observed that the CAC has no advisory role, employs an 0.5 FTE administration person and pays only sitting fees to family/carers. They also note the *Carers Recognition Act* was brought in as resource-neutral legislation and was at times felt to be simply *"ticking the boxes."*

The Office of the Chief Psychiatrist noted that they currently employ family/carers with lived experience to carry out monitoring, reviewing and auditing of services as part of review teams. They observed that the degree of carer involvement in systemic work is currently ad hoc and varies widely between services.

Some family/carers who were Carer Representatives on committees reported feeling unsupported and unheard in those roles and that their contributions were not valued. It could feel like being *"the token carer."* One family/carer described the system as ad hoc and noted the lack of systemic capacity-building to engage with family/carers.

Other important functions identified as part of a systemic advocacy role included providing training and education for clinicians, identifying service-level barriers to working with family/carers' and drawing attention to family/carer perspectives in meetings. Both individual families/carers and family/carer organisations identified access to information as a key issue for carers and saw a role for raising awareness of this issue with clinicians. A role was also identified for systemic advocacy work in forging closer links between government and non-government services.

Among service staff, some lack of familiarity with the role of family/carer peer workers in systemic advocacy was noted. This is perhaps unsurprising given the recent introduction of these roles in WA, with the first Carer Consultant employed in 2010. However, the clinical staff did express support for a consultant in the service who they could go to for advice. They also recognised the role of peer workers in culture change, alongside acknowledgment that this needs to come from many levels.

The families/carers expressed a desire for a professional body as well as sector leadership and training for peer workers in order to facilitate communication, training and support for peer workers. Although outside the scope of this report, they also expressed a desire for a funded systemic advocacy body, such as a peak body. Service providers who commented on this stated that a peak body can assist by providing a united voice on issues.

Policy work

The Mental Health Commission staff stated they would like to employ a Carer Advisor within the Commission. This was described as a facilitating, enabling role, involving policy work and informing the Commission how they could better communicate with family/carers. It was not described as a representative role. There was a hope that a Carer Advisor would have lived experience as a family/carer, in order to maintain links, have credibility with family/carers and function as a bridge between family/carers and the bureaucracy.

The families/carers expressed support for a Carer Advisor position. Without it, there was a feeling that family/carer peer workers on the ground would continue to face the same issues and *"run around at the bottom of the cliff."* It was also seen as symbolically important (although with care needing to be taken that it not be token). Longer-term, there was a desire to have Carer Advisors working across government, for example in the housing and criminal justice systems which also impact significantly on carers' lives.

The family/carer organisations saw a role for a Carer Advisor in research and policy development. However they expressed their concerns that a Carer Advisor position could be perceived as a representative role and that there would be a temptation for government to consult with that person to the exclusion of other family/carers and organisations. They were also concerned to ensure that their current access to government not be reduced due to them being directed to the Carer Advisor instead.

The staff at clinical services saw a role for a Carer Advisor in providing leadership around resourcing and developing the peer workforce, for example in developing resources, the evidence base and assisting with evaluations.

Whether family/carer workers need to have lived experience as a family/carer of a person with a mental illness

The family/carers emphasised the importance of workers having lived experience and the understanding, passion and insight this brings. A family/carer said, *"Otherwise it's just a job."* The families/carer noted that family/carers workers with lived experience often pick up on issues that workers who are not carers miss, saying *"We find that people who don't have the lived experience miss too many points."* Another family/carer said, *"What is not said is often as important as what is said."*

The family/carers highlighted the gap between the needs of consumers and families and what services provide – often in contrast to service providers' beliefs that they are meeting needs. They stressed the heightened awareness of the issues and realities of family/carers' lives that workers with lived experience bring and their role in raising awareness. The family/carers also saw a benefit of employing peer workers in helping shift clinicians' perceptions of family/carers.

It was noted that many of the family/carers who attended the forum are currently carrying out significant family/carer peer work on an unpaid basis (including peer support, individual advocacy

and systemic advocacy work). They wanted it to be recognised that this work is *"not just token, it's a job."*

The family/carer organisations do not currently require staff to have lived experience as a family/carer, other than the ARAFMI Carer Advocate position, for which it was a 'desirable' criteria. One organisation expressed its intention to move in this direction. Some staff emphasised the importance of workers with lived experience having other relevant skills and/or experience as well, to enable them to work effectively in the role and not be left vulnerable, particularly in services where levels of support for peer work vary. Other staff believed it was more important for workers in clinical settings to have credibility and know how to communicate with clinicians.

Some families/carers and service staff stated that whether lived experience was required could depend on what the role is intended to do. For example if it was case management, the skills and competency to do that were essentially what was required.

The family/carer organisations and individual family/carers noted the difficulties experienced by family/carer peer workers in clinical settings in particular and in confronting the negative attitudes of some clinicians. It was emphasised that where peer workers are employed, strong systemic structures and supports must be put in place.

Again, the policy stakeholders believed a Family/Carer Advisor in the Mental Health Commission would need to be a person with lived experience as a carer to have credibility with carers.

Sectoral readiness to employ family/carer peer workers

Policy stakeholders expressed support for carer involvement in policy development and high level decision-making, including the Carer Advisor position in the Mental Health Commission. The Mental Health Commission staff stated that both government and non-government mental health services have the capacity to employ Consumer and Carer Consultants. A preference was expressed to encourage rather than drive or require that at the present time. They noted that NGOs can convert existing positions to peer workers within their existing funding. However, the NGO and clinical service providers did not consider this as adequate or viable beyond a very limited scope. They emphasised the need for additional funding to establish and embed family/carer peer work in the sector.

The staff at clinical services acknowledged there was a way to go before peer workers could work alongside clinical staff comfortably. They acknowledged mistakes had been made in early experiences of employing both consumer and family/carer workers. They also noted the learnings which had come from employing peer workers, including the importance of having clear position descriptions and expectations, ensuring that relevant clinical staff are onside and having appropriate supervision arrangements. The progress that has been made was also noted, for example in consumer peer support workers becoming embedded in a service since its implementation. In general, there was greater familiarity with and understanding of peer support work as compared to systemic advocacy.

The family/carer organisations were very concerned that family/carer peer workers in clinical services have adequate supports in place rather than being employed as a change agent without this. Important aspects included training, support and a pay level that reflected a valuing of the role. However it was also noted by staff within both the clinical sector and the community sector that it was difficult to draw too many learnings from the limited experience at PaRK, and that future development could not be solely determined based on experiences of the implementation of a sole

position. The opportunity to share knowledge and work collaboratively (for example between carer organisations and clinical services) was seen as welcome.

The family/carers wanted to be involved in the further development of peer positions, specific to their needs and experiences in WA. They wanted to see clarity around the specific tasks family/carer workers would do and what the outcomes for families/carers would be. The family/carers also emphasised that the establishment of peer work positions needs to be done in co-ordination with other change in the mental health system, as the changes required will not happen in isolation.

Whether family/carer peer workers would be better employed within government/clinical mental health services or externally, for example by a family/carer organisation

Differing views were expressed on whether it would be more effective to employ family/carer peer workers within government/clinical mental health services or externally, for example in a family/carer organisation. These were based on both previous experience in employing consumer and carer peer workers in WA and from knowledge of the issues which have arisen for peer workers nationally and internationally.

Some stakeholders expressed a preference for employing family/carer peer workers within NGOs, who would then be based wholly or partly in clinical settings. This was based on the idea that this model makes it easier for peer workers to access support, maintain their peer function with clarity and advocate more effectively. However it was acknowledged that this can make it more difficult for peer workers to gain acceptance by clinical staff. It was noted that peer workers employed by government services had already experienced difficulties in gaining acceptance by clinical staff and this was expected to be magnified if workers were employed by an external agency. For that reason, clinical staff preferred that peer workers be employed by the clinical service. Again it was acknowledged that experience of these roles in clinical settings was limited and that leadership in further implementation would be desirable.

Government services employing peer workers was also seen to allow for building positive relationships with clinical staff, provide an 'internal voice' on family/carer issues and the provision of training and education as required. The presence and input of a Carer Consultant was seen as increasing staff awareness of family/carer issues. The process was seen as one of change management, in incorporating peer positions into clinical services and teams. The family/carer who had been employed as a Carer Consultant at PaRK supported the continuation of the position within the Area Health Service, with recommendations for change to facilitate the effective functioning of the position in the future. The service also intended to continue with the position and was recruiting to fill it at the time of the consultations.

Other stakeholders supported the use a range of models as appropriate and the employment of peer workers in both government and non-government services over time. Family/carers noted that the policy shift in focus from government to non-government services meant that the need is great in both.

Enablers and barriers to employing family/carer peer workers

All stakeholders acknowledged difficulties which have been experienced in employing consumers and carer peer workers, both in WA and elsewhere. Stakeholders identified factors which had assisted or hindered the process.

The clinical staff identified leadership, support and having 'champions' in upper management as critical to the success of peer work programs. Conversely, barriers to communication with higher levels of management represented a challenge. There was a belief that having peer workers report to and/or provide a link to the Executive level would make the roles significantly more effective.

In one service's experience, difficulties had arisen including due to a lack of clear role definition and supervision arrangements. The family/carer who had been in the role recommended that the service clarify and appropriately title the role, in terms of whether it was focused on peer support or systemic advocacy work. It was suggested that supervision be provided according to the needs of the worker and be in line with what was available to other hospital staff, as well as supervision specific to the peer role. This was identified as particularly necessary given that the role was new to the service and WA. Stakeholders also recommended that access to various levels of service management and decision-making bodies be provided, appropriate to the functions of the role. A family/carer organisation suggested that external supervision may also assist.

The family/carers identified the importance of addressing the status and power imbalance between peer workers and mental health professionals, noting,

> *"Carers live with a wide range of emotional and practical consequences of caring."*

They emphasised that some family/carers have low socio-economic status and may not have completed a lot of formal education. Professionals may also have negative views of families/carers, including due to difficult interactions with families/carers who have been traumatised or angry with services. These factors can mean family/carer peer workers are marginalised and sidelined, leaving their involvement as token.

One suggestion to reduce the power imbalance and provide additional support was to employ more than one peer worker in an organisation, for example through job share arrangements. Similarly, a suggestion was made that committees consist of equal representation, for example three consumers, three carers and three clinicians. It was commented that would also better reflect the breadth of experience of families/carers, as it is unfair to expect one person to represent all family/carers.

The importance of adequate training for peer workers was emphasised by al stakeholders. A family/carer said, *"One day is not enough."* Several family/carers had participated in the recent six month training 'Allies and Change', on leadership and advocacy skills and had found it valuable.

The clinical staff raised the question of effective recruitment policy. For example, some services which had employed consumer peer workers recognised that early on, they had employed consumers who were not well enough to be in the roles. This had resulted in high turnover and combined with the low number of hours worked had made it difficult to embed the programs. There was an increasing understanding of the need for relevant skills and work readiness. Similarly, it is increasingly recognised that family/carers require relevant skills in addition to lived experience. There was hope that the introduction of the Certificate IV in Mental Health Peer Work would make this easier. In one service, the possibility of structured opportunities such as work experience and placements also existed.

The staff reported that a high turnover in supervision and responsibility for peer worker programs had been challenging. Management and supervision provided by staff who were supportive of the program had provided needed consistency and development of the service. Co-locating peer

workers with teams which were more hospitable assisted. Conversely, placing peer workers within teams which had not been involved or prepared for their introduction or supervision was a barrier.

Difficulties were noted in introducing peer work roles where a culture was entrenched, with change to reflect government policy being slow on the ground. Resistance to change was encountered, as well as a lack of valuing of the contribution peer workers can make.

Being clear about definitions and expectations of the role with the worker undertaking it was key for a positions' success. For example, a lack of clarity about whether a role was primarily intended to provide peer support or carry out systemic advocacy in the service had resulted in difficult experiences for both the worker and supervising staff. Preliminary work and education with staff and management was described as very important, including clearly communicating what the role of the peer worker is to all staff. This can be particularly important with systemic advocacy work, which there may be less understanding of than peer support.

The families/carers identified support for peer workers as critical. They noted that estrangement between peer workers and other family/carers can occur where a worker is trying to hold both a family/carer perspective and that of an employee. This can also occur due to the power imbalance between being a paid worker and the frequently very disenfranchising reality of the experience of being a carer. Support and networks for peer workers were identified as important to counter this.

Staff supervising peer work programs in different services had also set up informal network and identified these as useful supports. Staff expressed a desire for formal communication and networks and a desire to connect with others doing similar work nationally.

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TABLES and APPENDICES

Table 1: Carer peer positions around Australia

Note: 'Carer representatives' are not included in this table as detailed discussion of them falls outside the scope of this report.

Role / position title	State	Employed by	Types of work carried out	Setting of service provision
Carer Advocate	Vic NSW WA	NGOs	• Independent casework advocacy (in person or by telephone), including: - attendance at family meetings - facilitating improved communication between carers and mental health services - advocacy in carers' interactions with other service systems, eg. Centrelink, State/Public Trustees, criminal justice system • Conflict resolution framework • Non-adversarial	• NGOs
Carer Consultants (called family/carer specialists in NSW)	NSW Qld SA Vic WA	Usually, Area Mental Health Services	• Sitting on service committees and attending meetings to provide a family/carer perspective • Providing training to staff on family/carers' experiences and needs • Providing secondary consultation to staff • Consulting with other families/carers and feeding their views back to the service • Having input into policy, strategic planning and service development • Creating family/carer-friendly resources such as information sheets, information packs and newsletters • Participating in accreditation processes • Sometimes, providing direct support for family/carers	• Usually, clinical services, in hospital or community mental health services

'COPES' and 'Caring Together' carer peer support	NSW Vic	In Victoria, ARAFEMI, with funding through partnerships, including with NGOs, respite and clinical services	•Support, information, education and referral	•Acute (inpatients) and community (NGO) settings – so 'sitting between' community and clinical services •Works 2 days/week, including one evening at the hospital as many carers visit their family member after work
'Families Helping Families' project (Orygen Youth Health)	Vic	Orygen (clinical service for young people aged 15-24)	•Family peer support workers phone every family new to the service. The consent of the young person is not required, in recognition that families need support in their own right. Provide information and emotional support, link to information sessions provided by clinicians, family resource room and family support groups	•At clinical service
'Family and Carer Support Services'	NSW	NSW Health funds NGOs to provide support services across NSW. There is one NGO service provider for each Area Health Service.	• Education and training packages which teach families and carers about mental illness and its management and help to build coping skills and resilience •Individual support and advocacy services for families and carers of people with a mental illness •Infrastructure support for peer support groups	•Note that people employed by NGOs in these programs do not require lived experience as a family/carer (may be desirable) •Positions created in these programs include Carer Advocate, Family and Carer Support and Development Officer and Family and Carer Education and Training Coordinator
'Friends Together'	Qld	Carers Qld	•Trained staff link carers together to provide 1:1 mutual support, through a buddy or mentoring system. There is a matching process.	• Once matched, carers support one another in the community

Carer Mentor program	SA	Carers SA	The Carer Mentor Program operates within each Carers SA local carer support region. The mentor program offers the opportunity for carers of a person with a mental illness to another mental health carer who has had success seeking support. The program provides the opportunity to share caring experience, knowledge and through the process grow and develop. • This is a developing program, in which interested carers are linked with a past or current carer who acts as a volunteer mentor. Types of support provided vary according to local need but include: - Mentors making initial phone calls to carers to provide emotional support, then linking them to a paid worker - Mentors offering support to carers who are attending an activity or support group for the first time to make it less daunting - Providing additional support in remote areas where paid workers are not always able to attend in person due to funding constraints	• Community
'Well Ways' emotional support service	Qld	Mental Illness Fellowship	• In rural Queensland, MIF piloted an emotional support service offered to carers participating in the Well Ways program as an additional, one to one peer support	• Emotional support, advocacy and liaison with health professionals were provided on a one-off, intermittent or regular basis over weeks or months. The service was provided by a family/carer who was also a qualified allied health professional.

Consumer and Carer run Mental Health Activity and Resource Centres (MHARCs)	SA (rural areas)	Run by non-profit organisations (often volunteer-based but with some paid co-ordinators)	• Aim to provide respectful, supportive spaces and opportunities for social interaction, skills development, education, information and recreation	• Community-based locations in rural areas
'Paying Attention to Self' (PATS)	Vic NSW	Designed by the Royal Children's Hospital Centre for Adolescent Health; now provided by a range of NGOs and local government services	• Peer support program for young people aged 13-18 with a parent affected by a mental illness • Core focus is peer support groups, which meet weekly for 8 weeks. They are co-facilitated by a young person with a parents affected by a mental illness and a health professional • Aims to provide young people who have parents with mental health issues with the opportunity to share their experiences and be supported by other young people in a situation similar to their own • The overall goal of PATS is to reduce the likelihood of the development of mental health difficulties in young people who have been identified as being at increased risk. The focus of the program is therefore on mental health promotion and illness prevention.	• Clinical mental health services, community health services, NGOs and local government services

Table 2: Summary of main carer peer worker models, including advantages and disadvantages

Name of Position	Employed by	Types of work carried out	Advantages	Disadvantages
Carer Peer Support Worker	• Community organisation (eg. family/carer organisation)	• Provide information to families/carers, eg. about impacts of mental illness on the family and referrals to carer support services • Assist family/carers to find their way around the mental health service system • Provide emotional support which can reduce isolation, guilt, shame and helplessness and decrease stigma • Help family/carers develop skills such as communication, problem-solving, crisis management, coping and self-care • Talk to staff at the mental health service on family/carers' behalf	• Can work from both a community organisation and the hospital • Model in which every family is telephoned at their first contact with the service can overcome initial barriers families experience to seeking support	• May be more difficult for worker to build relationships with clinical staff and gain acceptance and a valuing of role given that worker is not an employee and not based at the hospital all the time

| Carer Advocate | • Community organisation (eg. family/carer organisation) | • An independent person to advocate alongside family/carers where they have been unable to resolve a problem themselves or with the support of other workers. For example, an advocate can:

- talk to staff at the mental health service on family/carers' behalf

- attend family meetings at the mental health service with family/carers

- talk to other services family/carers have had problems with, eg. Centrelink, Public Trustee, criminal justice system

• Ideally, an advocate has a social work and/or legal background

• Ideally, an advocate uses a non-adversarial, conflict resolution framework to try to find a solution that is agreed by the consumer, the family/carer and the service | • Use of a non-adversarial, conflict resolution model seeks a solution which is agreed by the consumer, carer and the service

• Involvement of a skilled, independent person can make it easier for complex issues to be resolved

• Can be co-located with other carer support services. This means all referrals can be facilitated by a single point of entry which triages and directs calls to the Carer Advocate and/or other services (eg. peer support) as appropriate | • Need to develop relationships with mental health services and other stakeholder groups so the Advocate is seen as an asset and resource rather than an adversary |

Carer Consultant	•Hospitals or clinical mental health services in the community (Area Health Services)	•Advocate to improve the service based on family/carers' experiences and needs •Provide a voice for family/carers' experiences and needs in staff and committee meetings •Provide consultation and training to staff on carers' perspectives and needs •May provide direct information and support to families/carers (as with a Peer Support Worker, above) •May provide access to crisis funds	•Can make change 'from the inside' •Change at a systemic level •Can build relationships with clinical staff •Can improve professionals' understandings of carer experiences and needs	•Role conflict and possible conflict for the consultant in being an employee of the service and needing to advocate for change while maintaining positive workplace relationships •Role conflict and possible conflicts for the consultant in being an employee if a family/carer client isn't happy with the service and needs support to advocate and/or make a complaint
Carer Advisor (given various titles in different states)	•Relevant government department: in WA, Mental Health Commission	•Provide advice on mental health carer policy; liaise with family/carers and family/carer organisations in relation to mental health service reform, planning and evaluation	•Promote understanding and awareness of carer issues within government; provide carer input into policy development; facilitate improved access to government for carers and carer organisations	•Need role clear definition and appropriate supports built into role

Carer peer positions internationally

New Zealand

Peer support and advocacy

"All District Health Boards have a contract with an NGO to deliver family, whānau support in mental health and addictions ranging from 1-6 FTES. The largest NGO provider is Supporting Families in Mental Illness who hold about 80% of the total contract across the country. About two thirds of the fieldworker staff will have family, whānau member experience so it is seen as desirable but not essential and generally the role is seen as one of providing support, information and advocacy to family, whānau who are supporting someone with mental health and addiction issues.

Supporting Families in some parts of the country have set up a peer family volunteer system. An innovative approach to deliver Peer Family Support and education is with an NGO called Equip. They use one FTE to deliver family, whānau groups. The purpose of the groups are: To build a comprehensive support structure for the families and friends who are supporting people with mental health issues and to help them cope with supporting their loved one through knowledge, support and self-development."

Systemic advocacy

"Most District Health Board (DHB) mental health services have appointed a family, whānau advisor to carry out service development work and systemic advocacy to support family, whānau participation. A few DHBs have contracted this systemic role out to an NGO such as Supporting Families in Mental Illness, a national organisation, however most are employed as part of the DHB. Lived experience as a family, whānau member supporting someone with experience of mental illness or distress is seen as generally essential for the role as it provides a reference point when training staff, working alongside consumer advisors and talking to families, whānau."

Policy work

A National Family Advisor position is based with the Child and Adolescent Mental Health workforce programmes. There has also been a Family, whānau position at the Mental Health Commission however this has ended as the Mental Health Commission itself is winding up, with the sole position of Mental Health Commissioner to be based at the Health and Disability Commission. Lived experience as a family, whanau member is seen as essential for these positions.

(Information provided in personal correspondence Family, Whānau Advisor at Auckland District Health Board Mental Health Services, 27 October 2011.)

United Kingdom

Information provided by United Kingdom services indicates that family/carers with lived experience are fulfilling a range of roles, including the following:

- One-to-one practical and emotional support
- Advocacy
- Facilitating peer support groups
- Online peer support
- Paid support workers acting as 'friends' within the system, carrying out carers needs assessments which are used to direct carers to appropriate support services
- A drop in facility for carers to come and talk to volunteers who are also carers
- Trained volunteers (usually former carers) providing telephone support for carers over 50. This involves a weekly or fortnightly phone call of about half an hour, to provide the carer with an independent and supportive person who has had similar experiences to talk to and the opportunity to discuss their caring role in confidence.
- Presenting carer issues at Mental Health Trust induction programs
- Providing training to mental health professionals
- Working within a Social Enterprise to carry out surveys of other carers into what they think of services being provided

Scotland

The Scottish Recovery Network has produced Guidelines to support the development of consumer peer worker roles in Scotland (Scottish Recovery Network, 2011). These include detailed and practical steps in understanding peer support and implementing peer worker roles.

United States

A survey by the National Federation of Families for Children's Mental Health found 13 states out of 22 reported employment positions for families in their state mental health agencies (National Federation of Families for Children's Mental Health, 2008).

Several states in the US have certification programs for Parent Support Providers. A National Certification process is currently being developed, which was expected to commence in October 2011. The primary purpose of certification is to ensure that people employed in the field in any state meet consistent and high standards of performance. The national certification will require:

- Demonstration of specific knowledge, skills and abilities based on a national standard
- Adherence to a set of standards of practice in ten domains of core competencies
- Adherence to a Code of Ethics
- On-going training requirement for re-certification

- Required peer supervision

The focus of the parent support service is on empowering parents and caregivers to parent and advocate for the child/youth with emotional, mental or behavioral health related disorders or challenges. The scope of the service involves assisting and supporting family members to navigate through multiple agencies and human service systems (eg. basic needs, health, behavioral health, education, social services etc). It is strengths-based and established on mutual learning from common lived experience and coaching (National Federation of Families for Children's Mental Health, 2008).

Appendix A: Example position descriptions for carer peer work positions

The following examples are extracted from position descriptions for family/carer peer workers. Some service identifying details have been removed. They are intended to illustrate the roles, responsibilities and skills required.

Carer peer support worker #1

Position Duties

Role Implementation

- Work collaboratively with the PHaMs team, organisation Family Support program, community partners and Area Mental Health Service to develop a carer peer support service
- Develop promotional materials and marketing strategies
- Network and liaise with key carer and relevant community organisations
- Develop program structure, policy and protocols
- Provide regular feedback and evaluation (internal and external partners)

Service Delivery
- Promote agencies and service as well as information to key identified carer groups and stakeholders
- Assess and provide peer support to new and existing carers/family of clients engaged within the PHaMs program and Area Mental Health Service
- Provide support to families and carers with advice, reassurance, links, information and educational support
- Equip families and carers with some basic coping strategies and how these can be applied to individual situations
- Assist families and carers to overcome isolation in their experience of dealing with a relative or friend who has a mental illness / homelessness
- Facilitate families and carers to become more informed about mental illness / homelessness
- Provide direct support to carers utilising a recovery and peer framework
- Seek out key communities in the region, including CALD communities to explain and promote the value of carer and family support
- Support family/carer inclusiveness in service development
- Assist Area Mental Health Service to effectively develop opportunities to expand peer support within the delivery of clinical mental health services

Internal/organisational
- Establish effective working relations with the existing outreach teams and family services workers as well as other staff and volunteers within organisation
- Comply with relevant program policies and reporting mechanisms, standards of document handling and carer confidentiality.
- Maintain Occupational Health and Safety standards

- Take responsibility for continued learning using current research plus attending learning opportunities such as courses, training days and conferences
- Participate in Staff and Team and any external meetings as required
- Participate in direct supervision and team supervision
- Undertake any other duties as required by the Team Leader

Key Selection Criteria

Essential

- Direct personal experience, as a family member or carer of a person with a mental illness and the ability to utilise own experience constructively for the benefit of others
- Demonstrated understanding of the impact of mental illness / homelessness on consumers, families and carers
- Demonstrated understanding of peer support models
- Demonstrate a commitment to carer advocacy
- Highly developed communication and interpersonal skills
- Have the confidence and resilience to work with family stress and crisis
- Demonstrate a capacity to engage with, and work with carers and families including multicultural families, to develop and implement responsive approaches and supports.
- Basic understanding of Clinical Services, the PDRSS and housing sectors
- An ability to build collaborative relationships and network with stakeholders
- The ability to monitor and evaluate service effectiveness and make appropriate service recommendations / modifications as required
- Computer literacy in Word and Outlook
- Ability to inspire, be innovative and motivate others
- A current Driver's License

Desirable
- Relevant qualifications within the human services field

Carer Consultant #1

Role Statement

The Carer Consultant will provide direct support and information to carers; collaborate with service providers to improve individual involvement of carers in treatment and care plans of consumers; increase carer participation to develop the carer perspective in service, planning, delivery and evaluation throughout NWAMHS.

The Carer Consultant reports to the NWAMHS Area Manager via the NWAMHS Executive Carer portfolio holder. The position will provide a key link between carers and providers of the mental health service, and the Carer Consultant will provide advice to the Area Executive on matters relating to the needs of carers.

Position Requirements

1. **Provide support and information to family and other carers**
   1.1. Provide individual and direct support to family/carers, by engaging in telephone and/or face-to-face contact with families and other carers of people with mental illness
   1.2. Promote methods of self care
   1.3. Inform family/carers about support groups, counselling services, carer respite services, carer support brokerage funds and education programs as appropriate
   1.4. Provide information to family/carers, including provision of information packs, glossaries and service contact details
   1.5. Support Culturally and Linguistically Diverse (CALD) carers by listening to and understanding their experience of mental health issues, being sensitive to cultural norms and as appropriate the promotion of use of interpreters
   1.6. Support families/carers to be aware of their rights and responsibilities
   1.7. Participate in the management and administration of the carer support brokerage fund throughout the organisation's services and programs.

2. **Work collaboratively with other staff and consumer consultants to develop a coordinated approach to the needs of family/carers**
   2.1. Promote partnerships between the service and families/carers including joint meetings between carer, clinician, and consumer in order to facilitate management plans, discharge plans, quality improvement initiatives, and procedures for early intervention in case of relapse
   2.2. Promote carer participation in service planning, implementation and evaluation
   2.3. Work with the Area Manager (or senior delegate) and Consumer Consultant to support the role and development of the Consumer and Carer Advisory Group (CCAG)
   2.4. Carer Consultant, together with the Consumer Consultant will represent the service at the CCAG and provide feedback.
   2.5. In collaboration with carers, managers and staff representatives develop a Carer Participation Plan for the service.
   2.6. Participate in the recruitment of managerial and clinical staff, and where possible in other identified positions, such as reception/administration staff

3. **Education**
   3.1. Develop strategies with other staff to promote, organise and facilitate family/carer forums and education sessions, including education sessions for CALD families and carers and ensure that they met the needs of families/carers
   3.2. Promote and contribute to family/carer education sessions to ensure that information about mental illness is clear and readily accessible
   3.3. Contribute to staff training sessions on family/carer issues, through provision of a family/carer perspective
   3.4. Promote the perspectives and needs of families/carers in the choice and planning of staff training
   3.5. Encourage and support families/carers to contribute directly to staff training sessions.

4. **Administration**
   4.1. Demonstrate ability to work independently through good time management and meeting of deadlines
   4.2. Assist with the development of systems for gathering and recording information about carer contact s and experiences
   4.3. Provide feedback regularly on family and carer issues to the service either verbally or in writing
   4.4. Keep all notes and working records secure
   4.5. Understand and abide by ethical principles, confidentiality and duty of care
   4.6. Consider and incorporate occupational health and safety principles in all planning, interventions and contact
   4.7. Contribute to the development and review of policies and procedures.

5. **Professional Development**
   5.1 Undertake relevant training or professional development
   5.2 Participate in relevant peer support opportunities, including the Carer Consultant Network Victoria (CCNV) and VMHCN (the peak mental health carers' body) meetings and activities
   5.3 Receive regular supervision and opportunities for defusing
   5.4 Participate in an annual personal performance appraisal with line manager.

Key Selection Criteria

Essential
- Lived personal experience as a family member or carer of a person with a mental illness, and of the public mental health system
- Broad understanding of the impact of mental illness on families/ carers, including the consumer.
- Ability to communicate effectively with a wide variety of families and carers, staff and relevant portfolio and committees members
- An understanding of the diversity of the cultural and linguistic backgrounds of our community and the impact this has on consumers' and carers' experiences of mental illness
- Demonstrated ability to work independently
- Experience in providing a carer perspective to mental health services
- Demonstrated ability to advocate on behalf of carers and a willingness to advocate on behalf of the service

- Computer literacy

Desirable
Current driver's license

Carer Consultant #2

Role Title
Consumer / Carer Consultant

Purpose
The Consumer / Carer Consultant will promote, and give guidance to the development and ongoing management of consumer and carer participation. The position provides 'systems advocacy' in relation to consumer and carer related issues. The Consumer / Carer Consultant will provide advice in relation to the planning, delivery and evaluation of mental health service.

Your key responsibilities
- Fulfil the accountabilities of this role in accordance with Queensland Health's core values, as outlined above.
- Promote and assist with the development and management of a 'recovery approach', advocating consumer focused service delivery.
- Support the development and implementation of projects designed to deliver improved outcomes for consumers.
- Actively investigate and identify areas for improvement to service policy, procedures and protocols from consumers' and carers' perspective.
- Develop and facilitate effective consumer and carer participation in mental health service planning and delivery through a range of activities and forums.
- To act as a consumer / carer advocate in relation to the system of mental health service provision.
- Effectively communicate with consumers, carers, professional groups, and all service providers to assist in planning; delivering and evaluating a consumer focused mental health service.
- Build and maintain effective relationships and networks with community support and advocacy providers to assist in planning, delivering and evaluating a consumer focused Mental Health Service.
- Undertake consultative discussions with relevant National and State peak bodies for strategic purposes and provide reports and service recommendations in relation to consumer and carer participation and other projects to the Mental Health Executive.
- Identify ongoing and changing needs for consumer and carer participation within the mental health service and implement strategies to meet these needs.
- The position will provide regular reports and service recommendations to the mental health executive.
- Work in partnership with, and collaborate with the district Consumer and Carer Advisory Group (CAG) and/or other strategic advisory groups.
- Identify and support consumers and carers through collaboration, education, training and advice, to participate as consumer / carer representatives in formally established working parties and/or service committees.
- Assist in, and participate in, the planning, delivering and evaluation of training and education to mental health consumers, carers and mental health professionals as required.
- Support and provide advice to consumers involved in the 'Consumer Companion' program and support the mental health service in the ongoing management and development of this initiative.
- Participate in own Performance Appraisal and Development (PAD) process, seeking to develop self professionally.
- Participate in supervision and debriefing sessions as required.

- Comply with and utilise procedures, policies, regulations and standards which impact upon the position, including contemporary human resource management requirements and practices, such as workplace health and safety, equal employment opportunity and anti-discrimination policies.

Qualifications/Professional registration/Other requirements
- Applications from persons' with a lived experience of mental illness or carers of people with a mental illness would be highly desirable. While not mandatory, a relevant qualification would be well regarded.

(Please note that while this Position Description lists lived experience as a consumer or carer as 'highly desirable', a decision has since been made that it is a necessary criteria (Queensland Government, 2011.))

Are you the right person for the job?
You will be assessed on your ability to demonstrate the following key attributes. Within the context of the responsibilities described above, the ideal applicant will be someone who can demonstrate the following:

Knowledge
- Knowledge of contemporary national and state mental health policies and plans, and an understanding of mental health service provision issues.

Client focused
- Ability to empathise with and be aware of issues from the mental health consumer and carer perspective.
- Ability to demonstrated experience in the management of consumer and/or recovery focused programs and projects within the context of a mental health service.

Communication
- Ability to utilise effective communication skills including active listening and maintaining relationships.
- Ability to demonstrate oral and written communications skills including the ability to provide a range of correspondence including reports and presentations.

Team Work
- Ability to work within a team environment by showing respect and acknowledging and validating other team members.

Work Values
- Ability to demonstrate honesty, integrity and respect for all stakeholders including consumers, carers and staff.

District Consumer / Carer Consultant Coordinator #1

Purpose
- To undertake project activities relevant to the planning, development, monitoring and reporting functions of the local district mental health service. The position provides both operational support and administrative supervision to consumer and carer workers within their mental health service as outlined in the Clinical Supervision Guidelines for Mental Health Services (October 2009). The position also provides strategic advice and leadership around consumer and carer participation within their local district mental health service.

Your key responsibilities
- Fulfil the accountabilities of this role in accordance with Queensland Health's core values, as outlined above.
- The position reports to the Executive Director, Mental Health Service.
- Undertake project work in relation to the development, monitoring and evaluation of consumer and carer participation within the district mental health service.
- Provide advice and report on the progress of relevant aspects of activities to senior/supervising staff as required to ensure that activities are consistent with organisational requirements and that priorities and timelines are met.
- Liaise and consult with key stakeholders regarding the mental health activities, consumer and carer groups, and participate in the development of collaborative partnerships with service providers to ensure provision of quality services which are responsive to the needs of stakeholders.
- Exercise high level interpersonal, consultation and communication skills with stakeholders, team members and other service providers regarding quality improvement and service development activities.
- Participate as a member of a team in service development, evaluation and quality improvement activities to ensure continuous provision of quality services.
- Participate in information management activities including data collection, data entry and reporting local activities to contribute to service monitoring, evaluation and quality improvement activities.
- Maintain high level knowledge of district consumer and carer participation activities / initiatives and the supervision and training needs of consumer and carer workers whom report to this position.
- Provide ethical decision making in the achievement of organisational goals.
- Comply with and utilise procedures, policies, regulations and standards which impact upon the position, including contemporary human resource management requirements and practices, such as workplace health and safety, equal employment opportunity and anti-discrimination policies.

Qualifications/Professional registration/Other requirements
- While not mandatory, a relevant qualification would be well regarded. Applications from persons with a lived experience of mental illness or carers of people with a mental illness would be encouraged to apply.

(Please note that a decision has since been made that lived experience as a consumer or carer is a necessary criteria for this role (Queensland Health 2011.))

Are you the right person for the job?

You will be assessed on your ability to demonstrate the following key attributes. Within the context of the responsibilities described above, the ideal applicant will be someone who can demonstrate the following:

Knowledge
- Knowledge of contemporary national and state mental health policies and plans, and an understanding of mental health service provision issues.
- High level knowledge of mental health consumer and carer participation and relevant legislative and policy provisions relating to this group.

Client focused
- Ability to understand and respond to the expectations of district stakeholders, clients, consumers, carers and the community as a whole.

Problem Solving
- Ability to identify and resolve issues using an innovative approach and the ability to identify opportunities for improvement and resolve problems.

Team Work
- Proven ability to work effectively within a team setting to contribute to the development of project plans, deliver outputs and manage competing work priorities to meet agreed deadlines and commitments.

Communication and Interpersonal Skills
- Ability to develop, participate in and maintain relationships in an effective and motivated team environment.
- High level interpersonal, oral and written communication skills and proven ability in consultation, liaison and negotiation with team members, government and non-government service providers and clients and the ability to communicate complex organisational issues and prepare comprehensive correspondence, submissions and reports.

Carer Advocate #1

Duties

Intake and Information Systems
- Assess incoming referrals
- Access quality information resources to ensure provision of accurate and current information.
- Set and maintain clear procedures regarding the operation of the advocacy services and develop appropriate data recording.
- Liaise with staff responsible for intake and referral, to implement and operate a coordinated and accessible entry procedure for the Advocacy Service. This will involve liaising with the Telephone Helpline Staff and Counsellors to ensure appropriate triage and routing of incoming requests.
- Apply skills in supportive counselling to assist callers needing affirmation and support.

Individual Advocacy
- Ensure that carers understand their rights and responsibilities under relevant legislation and service policies and procedures.
- Advocate effectively on behalf of carers through negotiation and representation as required.
- Ensure that the advice and assistance provided is legally correct and in accordance with mental health practice and other legislative requirements.
- Provide referral to complimentary services for carers with other needs
- Identify and report on systemic issues.
- Undertake casework and case recording.

Representation
- Maintain and provide ongoing development of relationships with key advocacy, mental health and carer organisations in Victoria.
- Attend meetings and act as a representative of ARAFEMI.
- Contributes to the development of position papers in response to advocacy issues.

Education
- Form key relationships across metro and regional Victoria and facilitate the scheduling of CAST program throughout Victoria.
- Liaise with CAST trainers to coordinate delivery and support educative outcomes.
- Advocate and raise awareness of the need for greater education of workers across the mental health sector.
- Promote opportunities for ARAFEMI to engage in workforce development and training.

Reporting
- Develop and guide the implementation and evaluation of the ARAFEMI' advocacy service.
- Report to the Manager Family Services and Advocacy Reference Committee as required.

Other
- Ensure program processes meet best practice standards and are evidence-based.
- Establish and develop strategic partnerships to ensure long-term program viability.

- Carry out all duties in a safe working manner in accordance with ARAFEMI policies and procedures, and legislative frameworks.
- Maintain professional knowledge and qualifications, and be aware of statutes that may have special pertinence for their individual practice.
- Other duties, consistent with the role classification, as directed.

Selection Criteria

Essential:
- A commitment to social justice and the rights of carers of people with a mental illness.
- Experience interpreting legal material; preferably familiar with mental health legislation.
- High-level negotiation skills, and experience in conflict resolution.
- Advanced knowledge of the Victorian mental health system.
- Demonstrated experience providing advocacy advice, information, and provision of direct casework within the service and public arenas.
- Experience dealing with a diverse client mix including carers with complex needs.
- Ability to develop key relationships and work collaboratively with state-wide stakeholder groups.
- Identify a range of issues requiring referral to other agencies.
- Demonstrated project management experience including the development of project briefs, reporting, project implementation and evaluation.
- Advanced computer skills preferably use of Microsoft Office applications.
- A current Drivers Licence.

Carer Advocate #2

KEY ROLES AND RESPONSIBILITIES

Program Delivery

- Provide individually tailored information to carers
- Undertake individual advocacy for carers, as appropriate, and in line with the service's empowerment policies
- Provide emotional support to carers
- Provide education and training to carers
- Develop local resources for carers
- Facilitate carers involvement in local mental health services
- Develop and support carer support groups and family groups as appropriate

Administration

- Develop own work plan in cooperation with the Team Leader
- Maintain data collection and statistical records
- Provide regular reports to the Team Leader and therefore to the Manager Carer Assist and through this position to the senior staff and Management Committee of Schizophrenia Fellowship and the Area Health Service and Centre for Mental Health

Networks

- Liaise with Carer Assist and Schizophrenia Fellowship staff as appropriate
- Participate in Schizophrenia Fellowship strategic planning processes
- Link with local carer and consumer networks
- Liaise with Area Health Service staff, other non-government agency staff and professional networks as appropriate, including presentations on Carer Assist
- Link with local carers' projects run by the Schizophrenia Fellowship and other mental health NGOs, including ATSI and CALD projects as appropriate

Other

- Other duties as directed by the Manager Carer Assist or SFNSW senior staff.
- Adherence and compliance to the Continuous Quality Improvement policies and principles of the SFNSW.

Selection criteria

Essential Criteria:

- Knowledge of mental illness
- Experience in working with families and carers and/or people with a mental illness
- Knowledge of mental health services in the Area (or ability to acquire this knowledge)
- Excellent networking, interpersonal and written communication skills
- Demonstrated experience in working within the community development framework
- Proven problem solving skills
- Driver's licence and car

Desirable Criteria:

- Experience of caring for someone with a mental illness or disability
- Conflict resolution and advocacy skills

- Experience in the provision of training
- Knowledge of and experience in working with people from a culturally and linguistically diverse background (more important in some areas)
- Knowledge of and experience in working with people from an Aboriginal background (more important in some areas)

Carer policy advisor #1

Role title: Senior Project Officer, Carer Initiatives

Purpose
- To undertake project activities relevant to the planning, development, monitoring and reporting functions of the Consumer and Carer Participation Team including carer focused initiatives.

Your key responsibilities
- Fulfil the accountabilities of this role in accordance with Queensland Health's core values, as outlined above.
- The position reports to the Manager, Consumer and Carer Participation.
- Undertake high level project work in relation to the development, monitoring and evaluation of consumer and carer participation in mental health reform initiatives using project management methodologies and organisational skills.
- Provide advice and report on the progress of relevant aspects of project activities to senior/supervising staff as required to ensure that project activities are consistent with organisational requirements and that priorities and timelines are met.
- Liaise and consult with key stakeholders regarding the mental health reform agenda, consumer and carer groups, and participate in the development of collaborative partnerships with service providers to ensure provision of quality services which are responsive to the needs of stakeholders.
- Exercise high level interpersonal, consultation and communication skills with stakeholders, team members and other service providers regarding quality improvement and service development activities.
- Contribute to the development, implementation and evaluation of change management processes.
- Participate as a member of a team in service development, evaluation and quality improvement activities to ensure continuous provision of quality services.
- Participate in information management activities including data collection, data entry and reporting programs to contribute to service monitoring, evaluation and quality improvement activities.
- Maintain high level knowledge of carer participation activities / initiatives and the needs of clinicians to support consumers and carers to ensure high quality service delivery and promote awareness and understanding.
- Provide ethical decision making in the achievement of organisational goals.
- Comply with and utilise procedures, policies, regulations and standards which impact upon the position, including contemporary human resource management requirements and practices, such as workplace health and safety, equal employment opportunity and anti-discrimination policies.

Qualifications/Professional registration/Other requirements
- Experience of caring for a person with a mental illness would be highly desirable.

(Please note that while this Position Description lists lived experience as a consumer or carer as 'highly desirable', a decision has since been made that it is a necessary criteria (Queensland Government, 2011.))

- While not mandatory, a relevant qualification would be well regarded.

Are you the right person for the job?

You will be assessed on your ability to demonstrate the following key attributes. Within the context of the responsibilities described above, the ideal applicant will be someone who can demonstrate the following:

Knowledge
- Knowledge of contemporary national and state mental health policies and plans, and an understanding of mental health service provision issues.
- High level knowledge of mental health carer initiatives and relevant legislative and policy provisions relating to this group.

Client focused
- Ability to understand and respond to the expectations of stakeholders, clients, consumers, carers and the community as a whole.

Problem Solving
- Ability to identify and resolve issues using an innovative approach and the ability to identify opportunities for improvement and resolve problems.

Team Work
- Proven ability to work effectively within a team setting to contribute to the development of project plans, deliver outputs and manage competing work priorities to meet agreed deadlines and commitments.

Communication and Interpersonal Skills
- Ability to develop, participate in and maintain relationships in an effective and motivated team environment.
- High level interpersonal, oral and written communication skills and proven ability in consultation, liaison and negotiation with team members, government and non-government service providers and clients and the ability to communicate complex organisational issues and prepare comprehensive correspondence, submissions and reports.
- Capacity to apply reflective learning and willingness to receive feedback and undertake further development.

Information communication and technology skills
- High level project management skills with an ability to apply these skills to deliver outputs and business benefits within a multidisciplinary health care organisation.

Appendix B: Organisational features impacting the effectiveness of consumer consultant work

(Middleton et al., 2004)

Service Red: rigid and unresponsive
Characterized by:
. Consumer consultants not represented on management team.
. Consumer consultants' business in management committees discussed last or frequently deferred.
. Consumer consultants have no control of their own budget.
. Consumer consultant funding incorporates ''on costs'' resulting in the consumer consultant being paid less than others.
. Consumer consultant feels unsupported – supervision is either imposed or virtually non-existent.
. Consumer consultant called upon personally to represent consumer views, with little scope for incorporating the views of other consumers.
. Some staff in the organization actively opposed to increased consumer participation.
. Paternalistic attitudes prevail among staff towards consumers.
. Services tend to be more controlling of their consumers and less willing to take risks.
. Domination of the ''medical model'' of treatment.
. Consumer consultant not involved in, or member of a treating team.

Service Green: collaborative and enabling
Characterized by:
. Consumer consultant represented on management committee with regular time allowed for discussion on a wide range of consumer issues.
. Consumer consultant accountable for and controls their own budget.
. Consumer consultant is paid the full amount of the consumer consultant budget, and the service funds ''on costs'' of the program.
. Consumer consultant feels supported by the organization and is able to choose their own form of supervision, which occurs regularly.
. Consumer consultant encouraged to involve other consumers in expressing their views at all levels of the organization, with other services, and in the wider community.
. Staff are generally favourable to and value consumer participation.
. Staff actively seek consumer input into their own treatment
. Services more willing to take risks with consumers, and give them more responsibility for managing their own condition.
. Services incorporate broader approaches to psychiatry and make full use of the multidisciplinary team.
. Consumer consultant attached to a treating team, and more able to participate by offering a consumer perspective on treatment issues.

In reality, many of mental health services would not fall into either category. The point was made in one of the focus groups by a consumer consultant reflecting on their service that there might even be a case for conceptualizing a third type, an ''apathetic service'', which accepts the consumer consultant program but does little to actively support it, and listens to consumer feedback but does nothing to improve the service in the light of consumer recommendations. In this type of service staff are seen as neutral or apathetic about the consumer consultants role but not actively obstructive.