

**Being There: A Peer Support Service for
Older Adults with Mental Illness**

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Executive Summary

This document is the written report of a project commissioned by the Mental Health Workforce Development Programme. It discusses the development of a peer support service for older adult service users.

A review of the literature and relevant Ministry of Health policy documents confirms that recovery is the desired outcome for older adults with experience of mental illness. The ultimate responsibility for recovery resides with the individual, but it is much more likely to succeed if the social context within which recovery is expected to take place is positive and affirming. Peer support – defined as the coming together of people on a voluntary and equal basis for mutual aid – can contribute significantly to this positive social context.

In our consultation with major stakeholders it became apparent that there is a need for a peer support service for older adults with experience of mental illness. All stakeholders agreed that a peer support service for older adults would support recovery and fill a gap in service provision that has long been missing. The desire is for a service that:

- Fosters a collaborative, durable and safe relationship between the peer support worker and the service recipient;
- Will be safe, effective and ethical while also recognising that peer support workers may need to operate outside the boundaries understood by existing mental health service professionals;
- Is understood and promoted by the existing mental health service workforce; and
- Includes a degree of instrumental support in addition to its primary focus on providing emotional support.

Based on these findings it is recommended that a peer support service for older adults have the following characteristics:

- Autonomy from existing mental health services to retain the unique qualities of peer support;
- Be staffed by volunteer rather than paid peer support workers to reflect the special circumstances of older adults as peer support workers;
- If feasible, be integrated within an existing Non-Government Organisation;
- Intensive training and supervision of peer support workers to ensure safety, ethical practices and effectiveness;
- Education of the existing mental health workforce in the potential benefit to service users of a peer support service for older adults, and that the new service be allowed time to develop its identity along side existing services;
- The service be available at primary care level to increase accessibility and provide a preventive role for at risk groups;
- People with early-stage dementia have access to the peer support service to maintain fairness and to reflect the difficulty in separating early-stage dementia from mental illness; and
- Outcomes are measured through regular review of service user goal achievement and analysis of anonymous user satisfaction surveys.

Literature Review

Theoretical Perspectives

Recovery

The concept of recovery from mental illness is a relatively recent development. For centuries severe mental illness was seen as persistent and probably deteriorative. Society's response has been to incarcerate, devise crude and sometimes brutal "cures" and palliatives. The nineteenth century saw the beginnings of attempts at humane treatment, and from the early twentieth century came systematic efforts to understand the underlying nature of mental illness (Porter, 2002). Few thought that people with mental illness could participate in society as autonomous and capable human beings. From the second half of the twentieth century this approach came under increasing challenge. The development of anti-psychotic drugs in the 1950s pointed to the possibility of deinstitutionalisation, as did growing concern over the cost of institutional care itself. At a more profound level came the belated acknowledgement among policy makers and other elites that people with mental illness are entitled to the same ethical consideration and human rights as other members of society. Later research demonstrated that people with even the most severe mental illness can attain a level of function – with or without treatment – not previously thought possible (Harding, Brooks, Asolaga, & Breier, 1987). This conversion in attitudes led to the ideal of care within the community, even though this largely still meant exclusion from a full expectation of autonomy and participation within society. It is here that the concept of recovery attempts to provide the experience of mental illness with its long-missing dimension of quality of life, self-determination and control by consumers themselves over their own lives. Within the context of mental illness recovery means to reclaim one's life, and can be stated as "Living well in the presence or absence of mental illness" (Mental Health Commission, 1998).

Within the New Zealand literature there is a clear progression from acknowledgement of community as the appropriate therapeutic environment for people with mental illness (Mental Health Foundation, 1986), to an explicit repudiation of the "benevolent paternalism" of the traditional model now officially deemed "unacceptable today in mental health services" (Ministry of Health, 1995), to recovery as the declared goal of mental health care in New Zealand (Mental Health Commission, 1998). Yet it is not always clear what recovery means within the context of mental illness. The various mental health constituencies use the term freely but do not always agree on what it means. Recent literature even asks whether the term has attained the status of a shibboleth (Davidson, O'Connell, & Tondora, 2004). Jacobson and Greenley (2001) note that recovery is variously described as something individuals experience, service providers promote and systems facilitate, "yet the specifics of exactly what is to be experienced, promoted, or facilitated – and how – are often not well understood either by the consumers who are expected to recover or by the professionals and policy makers who are expected to help them" (p.482).

Part of the problem in articulating clearly the concept of recovery from mental illness is the nature of mental illness itself. Not only do people with mental illness suffer profound loss of self-identity and autonomy as a direct result of their condition, but must often confront its destructive consequences through loss of social identity, unemployment, poverty, stigma, abuse, rejection by family and friends, and the iatrogenic effects of treatment. The pattern of recovery from mental illness rarely follows a classical medical model of linear recovery from illness to restoration of original state. So devastating and lasting is mental illness and its consequences that it usually precludes return to an original pattern of life. An understanding of recovery is further complicated by the often episodic nature of mental illness, its association with impaired judgement, social withdrawal and patterns of behaviour which incite fear, stigma and discrimination in the wider community. The model of recovery from severe physical disability

does not quite fit mental illness (Deegan, 1992). A person with paraplegia can be said to have recovered in the sense that they have attained meaning and purpose in life despite the fact that their spinal cord remains severed (Anthony, 1993). However, people with persistent and incurable disabilities such as paraplegia, diabetes or blindness are not expected – as usually are people with mental illness – to overcome the symptoms or the visible signs of illness before they can participate as equals within society (Davidson, Stayner, Nickou, Styron, Rowe, & Chinman, 2001).

For Pat Deegan, the “concept of recovery is rooted in the simple yet profound realisation that people who have been diagnosed with mental illness are human beings” (Deegan, 1996). Recovery carries an implicit assumption of a supportive and accepting social environment. People with experience of mental illness have rarely had this. Recovery is as much a struggle for social acceptance and equality of rights as it is an individual claiming of life (Chamberlin, 1977; Deegan, 1988; Everett, 1994; Mead & Copeland, 2000; Unzicker, 1989). This means overcoming the inescapable negative reinforcement of “learned helplessness” (Seligman, 1975) which traditionally has characterised the experience of mental illness through internalised passivity, low expectations, self-stigma and belief that the future is determined by others (Chamberlin, 1978; McCubbin & Cohen, 2002). Two concepts are thus central to recovery. One is empowerment, which refers to a marginalised group’s attempt to take control over the processes that govern them (McCubbin & Cohen, 2002). The other is self-determination, which refers to the right of individuals to have control over their own lives (Cook & Jonikas, 2002).

For an individual, recovery is a deeply personal, unique process of transformation and growth beyond the catastrophic consequences of mental illness. Recovery is a path rather than a destination and it is a process unique to each individual (Anthony, 1993; Jacobson & Curtis, 2000; Ralph, 2000). It is often the mundane things in life that most people take for granted or think of as trivial that are cited as most important for people seeking to recover from mental illness. To highlight this, it is worth quoting in full Larry Davidson's summary of what we have learned so far from people in recovery from mental illness (Davidson, 2004).

The things that help recovery:

- Sense of belonging and acceptance from caring others;
- Renewed hope and commitment;
- Involvement in meaningful activities in the community;
- Redefining the illness as only one aspect of a multidimensional sense of self (rather than having my self and life defined by the illness);
- Finding ways to manage the symptoms;
- Experiencing successes and pleasure; and
- Reciprocity and giving back to, and regaining citizenship in, the broader community.

The things that hurt recovery:

- Being the object of stigma and discrimination;
- Experiencing repeated failures and losses;
- Losing control of my life, having others make important decisions in and about my life for me;
- The constriction of possibilities, expectations, and roles open to me;
- Being confined to a passive, patient role in which I have nothing to offer others; and
- Negative and paternalistic attitudes, accentuating my deficits and problems.

The responsibility for recovery resides ultimately with the individual, but it is much more likely to succeed if the social context within which recovery is expected to take place is positive and affirming. Thus, when we state recovery as a concept, it can be said to refer to two related and reinforcing processes: an internal process of change within an individual who is recovering, such as hope, healing and connection; and external conditions which facilitate recovery, such as a culture of healing and a collaborative relationship between consumers and providers (Jacobson & Greenley, 2001). Peer support – the principle that people who share a disability or problem have something to offer each other – can contribute significantly to the process of recovery from mental illness.

Peer support

Peer support can be defined as the coming together of people on a voluntary and equal basis for mutual aid. It is a counterpoint to the imbalance in power that is an inescapable fact of professional support. It embodies empowerment and self-determination through participation that is voluntary, a sense of control which is actual, an emphasis on the whole person and their strengths and potential, and an environment which is empathetic and free from the stigma and discrimination which sets people with experience of mental illness apart from their community. Peer support shifts the cultural context of mental illness from its identification as a medical diagnosis to a culture of reconnection and healing through social support and participation among peers (Mead, Hilton, & Curtis, 2001). From this theoretical perspective peer support can aid recovery by improving an individual's understanding of their situation, through reduced social isolation, the provision of positive role models and feedback which reduces self-stigma, assistance with problem-solving and coping-strategies, and by offering an identity and world view through which to make sense of one's experience (Campbell & Leaver, 2003; Corrigan, Calabrese, Diwan, & Keogh, 2002; Davidson, Chinman, Kloos, Weingarten, Stayner, & Tebes, 1999; Kennedy & Humphreys, 1994).

The literature on the effectiveness of peer support in improving quality of life is extensive (Kyrrouz, Humphreys, & Loomis, 2002). The literature on the role of peer support in recovery from mental illness is less extensive, and it has been suggested that lack of methodological rigour detracts from the value of much of the available research (Davidson et al., 1999). The problem, of course, is in measuring recovery from the highly individualised consequences, rather than the symptoms, of mental illness. Nevertheless, the literature is largely positive (Corrigan et al., 2002; Davidson et al., 1999; Sommers, Campbell, & Rittenhouse, 1999). Consumer-provided peer support can serve people who do not accept, or choose not to participate in, traditional services (Campbell & Leaver, 2003). Peer support has been shown to play a role in symptom reduction and rate and length of hospitalisation (Davidson et al., 1999; Magura, Laudet, Mahmood, Rosenblum, & Knight, 2002). There is evidence of the positive role that peer support appears to play in improved self-esteem, better decision-making skills and improved social functioning (Campbell & Leaver, 2003; Davidson et al., 1999). Significant evidence also exists on the role of peer support in extending social networks for people with mental illness. It has been suggested that even asocial and reclusive people who have withdrawn completely from social contact still yearn for social connection and friendship despite their apparent contentment in isolation (Davidson et al., 2001). Indeed, the importance of friendship, companionship and social networks in aiding recovery from mental illness is well-established (Froland, Brodsky, Olsen, & Stevens, 2000; Boydell, Gladstone, & Crawford, 2002). Even though it is a contrived relationship, peer support is integral to this process of reconnection and helping people with mental illness to step out of the social withdrawal and isolation that is so often a characteristic of mental illness (Corrigan et al., 2002; Boydell et al., 2002; Davidson et al., 1999).

Davidson et al. (1999) identify three forms of peer support: 1) naturally occurring mutual support; 2) consumer-run services; and 3) consumers as providers within clinical and rehabilitative settings. The latter two are more recent phenomena, offer more purposive and

structured approaches to support, and are more pertinent to this review. It is with these more structured services that the literature identifies the problem of relationships with existing mental health services. Whether provided by existing services or independently of them, health workers may see peer support as potentially dangerous to service users through potential exposure to misinformation, or threatening to professionals through the potential for an anti-psychiatry and anti-medication ethic to develop among consumers (Chesler, 1990). Consumers working closely with non-consumer professionals within existing mental health services can often be placed in particularly awkward situations. They need to balance their consumer and provider identities and may lose the very qualities as consumers which makes them so valuable. Service providers might not accept consumers as fully-fledged providers and they may no longer be accepted as consumers among peers (Salzer, 2002). Moreover, professionals may not have the skills to deal with people who are neither patient nor carer and may have had negative experiences with consumers which could carry into generalised marginalisation of consumer providers (McAllister & Walsh, 2004). There is also the danger of consumer providers being professionalised or co-opted into a predominant medical model of service provision that stresses social distance and detachment (Singer, 2002). While there will always be an initial assumption of equality between professionals and consumer providers, the nature of team dynamics will often regress to a hierarchical model with a predominant medical focus, which is in conflict with the values of mutual assistance among peers (Canadian Association of Gerontology, 2002).

The literature on consumer-delivered services is clear that services that are heavily dependent on professional involvement, funding and the personnel requirements of professional services risk losing their unique qualities and benefits (Campbell & Leaver, 2003; Salzer, 2002). Indeed, several works on consumer-delivered services and peer support stress the need for autonomy from formal mental health services (Sommers, Campbell, & Rittenhouse, 1999; Salzer, 2002; Campbell & Leaver, 2003). There is a simple rationale for this, consistent with the theoretical basis of both recovery and peer support: a peer support worker is attached to a person, not a service.

Older adults and peer support

The concept of recovery and its related literature rarely mentions older adults. Recovery is a transformational process. It focuses on hope and future possibilities. How older adults with experience of mental illness, often beset with loss, diminishing social networks and reduced physical capability, think of recovery has not been a focus of research. Nor is there a significant literature on the role peer support might play in the recovery process for older adults with experience of mental illness. A small literature points to possible benefits from various kinds of mutual aid and peer support for older adults with mental illness (Lieberman & Bliwise, 1985), but we know very little about the particular dynamics. There is a very large hole in the literature (Dein & Huline-Dickens, 1997; World Health Organisation, 2002).

It has been argued that exclusion from research is evidence of widespread discrimination and stigma against older adults with experience of mental illness (Hatfield, 1999; World Health Organisation, 2002). The World Health Organisation and the World Psychiatric Association's (2002) *Technical Consensus Statement* on stigma and discrimination against older adults notes that older adults with mental illness often face stigma and discrimination twice over in the form of a "double jeopardy" – discrimination and stigma for being old, and discrimination and stigma for having a mental illness. They argue that this is a significant barrier against older adults with mental illness achieving recovery and enjoying the quality of life they deserve (World Health Organisation, 2002). This suggests that the internal processes of recovery and external social and cultural factors which can either encourage or inhibit recovery may be of particular importance for older adults, and that this needs to be taken into account in the design of mental health support services for older adults.

Only fairly recently has there been widespread recognition that older adult's experience of mental illness differs from that of younger adults. The most important are age-related differences in presentation, special barriers to receiving care, and age-related developmental and social factors (Canadian Association of Gerontology, 2002). Loss of a loved one, isolation and loneliness through loss of social networks, frailty, loss of mobility, physical illness, the side effects of medications, inability to adjust to a new environment such as a nursing home, loss of purpose and identity through retirement or the inability to live an independent life can contribute to mental illness among older adults (Canadian Association of Gerontology, 2002; Dein & Huline-Dickens, 1997; Dwyer, Gray, & Renwick, 2000; Meador & Blazer, 1998; Richmond, Basket, Bonita, & Melding, 1995). Moreover, most older adults were socialised in an age when mental illness was particularly shameful, regarded as a personal failing and associated with the asylum. When combined with the stoicism often demonstrated by a generation which has experienced war and hardship the result is often denial of condition and refusal to seek help (Hatfield, 1999). Older adults are generally less well informed about mental illness than younger age groups, less likely to see any benefit from using mental health services and more likely to see mental health services as harmful (Fisher & Goldney). Although older adults are less likely to seek help from mental health services, evidence suggests that they can be receptive to mental health services once informed about them (Robb, Haley, Becker, Polivca, & Chwa, 2003).

Stigma and discrimination are major influences on the attitudes of older adults towards mental illness. Scambler (1998) identifies two types of stigma. Enacted stigma refers to actual discrimination grounded in perceptions of social and cultural unacceptability. Felt stigma refers to the shame of being identified as culturally or socially unacceptable combined with a fear of encountering enacted stigma. Felt stigma can be as damaging as enacted stigma since it often results in shame, guilt and withdrawal. The consequences of stigma within health services can be particularly harmful. An ageist belief that mental illnesses such as depression and anxiety are a normal part of ageing may result in failure to take the condition and its consequences seriously (Hatfield, 1999). The widespread belief that to some extent all older adults are "peculiar" may mean that psychoses or personality disorders may go undiagnosed, and the late consequences of early trauma may go unrecognised because older adults are often perceived as having no history (World Health Organisation, 2002). The ageist notion that older people are inflexible and incapable of change can reinforce popular and professional beliefs that older adults with mental illness cannot benefit from treatment or are incapable of recovery. And professional and family attitudes towards autonomy and the capacity of older adults to make life decisions may further inhibit recovery (Hatfield, 1999; World Health Organisation, 2002).

Negative cultural stereotypes may result in older adults accepting stereotyped explanatory models of their own illness and place in society to the extent that they may only reveal what they perceive society wishes to hear (Dein & Huline-Dickens, 1997; Hazan, 1994; Hazan, 1998). Hazan (1994) argues that if society sets the opportunities available to older adults to be either independent and appreciated or dependent and redundant then it also defines the meaning of being old. If older adults have control over their own lives then they will be able to construct meaning in their lives themselves. One's sense of self is greatly enhanced by the meaning in daily life that comes through having control over one's life. This is an important point. Recovery and peer support are reversals of power in that the service takes direction from the service user. The service user is no longer a passive user of services. This helps to overturn the learned helplessness traditionally so characteristic of both people with mental illness and of older adults. The importance of personal control is validated by research showing a positive association between perceptions of control and quality of life for older adults (Powers, 2004). Pearlin and Skaff (1998) cite evidence that reduced autonomy equates with vulnerability to stress, and note that social support fails most commonly if the recipient is denied a sense of control over their own lives. Support contributes to resilience among older adults with mental illness and helps to lessen stress. Even the perception of receiving support has been shown to reduce stress (Ryff, Singer, Love, & Essex, 1998).

Meador and Blazer (1998), in their study on the variability of depression in old age, suggest that the most effective way for older adults to create new meaning for changes that have occurred through loss of social support is to tell their stories. Peer support workers through a common experience of mental illness are equipped to assist this search for new meaning. Pearlin and Skaff (1998) note that while families have a deep commitment to caring and remain the major source of emotional and instrumental support for older adults even in situations characterised by conflict, they may not be the best substitute for a deceased provider of support. They draw on research showing that the most effective emotional support comes from peers with similar life experiences.

Practical Perspectives

Introduction

A consumer peer support programme for older adults will require four key training objectives: 1) peer support workers will need to work safely, ethically, and effectively with service users as required by the Mental Health and Health and Disability Sector Standards; 2) workers within the existing mental health service will need to understand the purpose and value of the new programme and how best to utilise its services; 3) staff in both the new and existing services will need to understand the implications of introducing a new method of service delivery; and 4) the special requirements of training older adults.

Mental health services in New Zealand are required to use the recovery approach (Mental Health Commission, 1998). Peer support workers will need training in all ten areas of the recovery competencies (Mental Health Commission, 2002) and how to apply the recovery approach to their daily practice. The Strengths Model, based on the premise that people who experience mental illness have the ability to learn, change and grow, is both consistent with the concept of peer support and a practical complement to the recovery approach.

To work safely and effectively, peer support workers will need a basic knowledge of mental health services, a skill base sufficient to enable them to perform effectively and continuing access to relevant information and support. To be ethically competent, peer support workers will need training in the theory and practice of ethics, decision-making, understanding the consequences of their actions, the duties inherent to supporting occupations, and the legal and resource implications of their work (Seedhouse, 1998).

Education of existing service providers

Organisational and cultural factors within services can impede successful consumer involvement. Providers may resist a peer support service if it is seen to compete for resources with existing services or take provider time away from other duties (Simpson, House, & Barkham, 2002). Clinicians with a deeply embedded medical focus may see little benefit in consumer involvement and decline to cooperate fully (Kent & Reed, 1998). Burns-Lynch and Salzer (2002) describe the termination after only one year of a peer-based service with a peer support component despite successful outcomes for its service users. Existing services had no incentive to refer users to the new programme, service providers could not realise the potential of peer support while committed to a traditional medical approach and the new service was not given sufficient time to embed into the existing service structure. The authors conclude that as much attention needs to be paid to facilitating the adoption of innovative services as is spent in their design.

The tendency of health workers to resist implementation of best-evidence practice has a well-established literature (Torrey, Drake, Dixon, Burns, Flynn, Rush et al., 2001; Michie & Johnston, 2004). Commonly cited reasons for service resistance to best practices are

insufficient clear guidelines, lack of awareness, disagreement with the guidelines, lack of outcome expectancy and inertia of previous practice (Cabana, 1999). Education alone does little to change practice. Guidelines need to be clear and written in behaviourally specific terms (Michie & Johnston, 2004). Multifaceted interventions which target different barriers to change are likely to be more effective than single interventions (Grimshaw, Shirran, Thomas, Mowatt, Fraser, Bero, et al., 2001). Practical solutions include a specifically developed “toolkit” to inform providers at all levels of service delivery of the new service. Administrators will require organised resources, effective education packages and policies and procedures aligned with the new service. Clinicians will require evidence followed by training programmes which allow opportunity for observation and, finally, supervision of their practice. Advocates will need skills and resources to enable effective lobbying for evidence-based practice (Torrey et al., 2001).

Referring mental health services will also need to be aware of the “inverse hierarchy” that results from adoption of the Recovery Approach and the Strengths Model (Rapp 1998). Traditional mental health services are hierarchical with the service manager or psychiatrist at the head. Service providers may find it difficult to accept a service that takes its direction from goals set by the service user.

Ethics, safety and boundaries

All health workers face the problem of how to define the boundaries between their professional duties and their personal preferences. Peer support workers have no clinical responsibility but confront many of the same ethical and boundary issues faced by clinical staff who engage with distressed and vulnerable people (Meehan, Bergen, Coveny, & Thornton, 2002; Dixon, Krauss, & Lehman, 1994). Yet the professional's detachment from the client emphasised by traditional models of care is neither possible nor desirable for peer support workers. A peer relationship is built on mutual respect, common experience and shared responsibility (Mead et al., 2001). Peer support is an antidote to the imbalance of power consumers often cite as a non-therapeutic aspect of the professional relationship. To insist upon rigid adherence to traditional notions of boundaries would negate the rationale for peer support.

Many service providers cite this necessary blurring of boundaries as an obstacle to hiring mental health consumers. Peer support workers may have dual relationships, the result of social relationships which extend beyond the professional/client relationship (Carlson, Rapp, & McDiarmid, 2001; Ministry of Health, 2001; Mowbray, Moxley, Thrasher, Bybee, McCrohan, Harris et al., 1996). Role conflict and confusion may result if a peer support worker is employed by the same service that provides him or her with services (Carlson et al., 2001; Salzer, 2004). Confidentiality may be an issue if a peer support worker has access to the file of someone with whom they are involved socially (Carlson et al., 2001). Peer support workers may feel obligated to provide significant instrumental support in addition to the emotional support prescribed by their role (Mowbray et al., 1996).

These obstacles need not be fatal to peer support. To overcome them, the literature makes a number of suggestions for inclusion in peer support training. These include training in policies and procedures found in service specifications designed to deal with potential boundary problems (Carlson et al., 2001). The development of skills to negotiate “flexible” boundaries (Mead et al., 2001), an approach which Davidson et al. (1999) suggest can help avoid the “professionalisation” of peer support. Mowbray et al. (1996) suggest an “educational campaign” designed to interpret role innovation, stimulate discussion on the nature of the relationship between professionals and peer support workers and increase awareness of performance expectations. An Australian study which assessed the impact of a 16 week training programme in peer support on the psychological well-being of its ten participants recommends a “code of conduct” to define the scope of practice for peer support workers (Meehan et al., 2002).

Basic knowledge and skill development

Peer support workers, like other mental health workers, require clear aims and a sound theoretical basis to their work. The Recovery Approach (Mental Health Commission, 2002) and its practical complement, the Strengths Model (Rapp, 1998), will provide peer support workers with this basis. One especially useful resource is the strengths-based training manual developed by Fast and Chapin (2002) for use with older adults.

This literature review also looked at peer counselling services developed in the United States in the 1980s and 1990s, and more recent peer support programmes in Australia and the United States. Drawing from these, the training requirements of peer support workers should contain the following elements:

- In order to liaise effectively with clinical services, peer support workers will need basic information on mental health terminology, diagnosis and symptom management (Meehan et al., 2002) including signs, symptoms, first aid and management of medication (Forchuk, 2004);
- A basic understanding of the physical and psychological effects of ageing such as impaired mobility, grief, loss and depression (Garcia, Metha, Perfect, & McWirter, 1997);
- Training in cultural safety. This is essential in a culturally diverse society (Mental Health Commission, 2002). As well as workshops on the Treaty of Waitangi, peer support workers will need to know how to access culturally appropriate resources for people of Pacific Island ethnicity. New Zealand's Asian population is growing rapidly. Peer support workers will need to understand the affect modernisation has on the mental health of older adults from more traditional societies where care patterns and the esteem with which older adults are held is very different from New Zealand (Dein & Huline-Dickens, 1997);
- Peer support workers will need training in stress management. Peer support workers often experience stress after engaging with "unmotivated" people or with persistent drug and alcohol users (Mowbray et al., 1996). Moreover, peer support workers are more vulnerable to stress than their professional counterparts because of the lack of clarity in their roles and from having to deal with discrimination from some service providers (Mowbray & Moxley, 1998);
- To ensure safe practice, peer support workers will need communication and counselling skills (Meehan et al., 2002; Forchuk, 2004; Garcia et al., 1997);
- To reduce the stress of working with people who are unaware of their ability to learn, grow and change, peer support workers will need training in motivational interviewing techniques (Mowbray et al., 1996);
- Peer support workers will need a sound knowledge of community resources and networks (Forchuk, 2004; Rapp, 1998);
- A working knowledge of the Mental Health Act and its legal implications (Meehan et al., 2002);
- A basic understanding of policies currently directing Mental Health Services at both a local and national level; and
- A person who is retired or been unemployed for several years may also need training in time management to help them to fit the work into their normal schedule and to make them more effective peer support workers (Mowbray et al., 1996).

Training methods

There is some debate over which method of training is most effective in encouraging health workers to make use of accepted best practice interventions. The relationship between

educational input and subsequent outcomes for service users is inconclusive (Jordon, 2000). In an overview of forty-one systematic reviews of intervention Grimshaw et al. (2001) concluded that until more rigorous research methodologies to evaluate training programmes are used, it is not possible to determine the most effective training method. However, their overview did find that “quality of care” was most likely to improve from the use of “multi-faceted” interventions. A training programme using both didactic and participatory methods seems most likely to benefit service users.

Ongoing education and supervision

All health workers require ongoing supervision and regular in-service training to ensure that they continue to provide a service which is safe, effective and ethical. Peer support workers are no different, and perhaps need closer supervision because they lack the institutional structures available to professionals. A policy of “supported peer support” recognises these difficulties (Davidson et al., 1999). The supervision and educational needs of peer support workers can be stated as follows:

- Frequent supervision sessions at the outset. Mowbray et al. (1996) recommend one hour of supervision for every four hours of client contact;
- Peer support workers will need training in how to make best use of supervision. Mowbray and Moxley (1998) noted that many peer support workers in their study revealed that they did not know how to use supervision, and deficits in training required supervisors to guide their practice closely and give positive feedback; and
- Older adults being trained as peer support workers may lack confidence and experience anxiety about their ability to perform their role. Hoffman (1983) noted that training may take up to one year and supervised placement can continue for an additional 15 weeks.

Special needs of older adults as peer support workers

In their respective studies of older adults as peers, Hoffman (1983) and Harman (1993) noted a number of issues. Older adults often lack confidence in their capacity to learn and this can reduce their ability to grasp new concepts. This can be addressed by slowing the pace of the training programme when compared to an equivalent adult course, and only invite participants to join the workforce when they feel that they are competent. Older adults also find it difficult not to give advice. Harman (1993) cites programmes where this was interpreted as failure to understand the concept of a client-centred approach. Hoffman (1983) notes that this instinct is difficult to suppress totally because trainees believed that their value as counsellors lay in their life experiences and own ability to overcome problems. Assignments designed to encourage trainees to correct their own mistakes helped to reduce this instinct to some extent. Making use of parallel process with trainees setting personal goals and outlining the steps to achieve them was successful in helping trainees to understand the process of changing behaviour (Hoffman, 1983). This technique could also be used to reduce hasty advice-giving. A third study that evaluated the training components of a peer counselling programme for older people with experience of depression showed benefits to the trainees. They described enhanced skill in interpersonal relationships and appreciated the opportunity to be a member of a close-knit group. However, some respondents indicated their dislike of some training activities, such as role plays and case presentations or times of conflict caused by personal disclosure (Garcia et al., 1997).

Methodology and Results

Scope of Consultation

Most of the consultation for this project took place in the area served by Auckland District Health Board (ADHB). ADHB provides health services for a multicultural population of nearly 400,000 people living in the central area of New Zealand's largest city. Health workers in two provincial areas in the upper North Island were also consulted to help better understand the needs of older adults living in small towns and rural areas.

Three major stakeholder groups were consulted: older adults who used mental health services; providers of mental health services for older adults; and family members of older adults with experience of mental illness.

Invitations for consultation were sent by email to older adult mental health services in the northern half of the North Island and participants from each provider group were selected based on their willingness and availability. Providers were asked to distribute the invitation to service users and family members but this produced only one volunteer, a family member. Participants from service user and family member stakeholder groups were recruited eventually through word of mouth, personal acquaintance and from among publicly identified service users such as people in consumer advisor or advocacy roles. Additional interviews were conducted with two Non-Government Organisation providers, two Ministry of Health officials and people able to provide Māori, Pacific Island and Chinese perspectives. A total of 42 people were interviewed either individually or within focus groups.

The interviews sought to determine if particular needs of older adults with mental illness could be addressed through the use of peers as support workers. Stakeholders were asked to define "peer" in the context of a support service for older people with experience of mental illness, identify the needs of older adults and specify how using peers as support workers might answer those needs. They were also asked to specify qualities they would expect to find in a peer support worker and what they would expect them to do, to make suggestions on the selection and training of peer support workers and identify some of the challenges that might face a peer support service for older adults with experience of mental illness.

Data Collection

A General Interview Guide Approach was used (Patton, 2002). A written interview guide was developed and sent to each respondent prior to the interview (see Appendix A). This approach enables the interviewer to adapt the wording and sequence of questions for specific respondents, ensures that the same topics are covered with different participants in each stakeholder group and allows the interviewer freedom to explore lines of enquiry relevant to the respondent's level of experience or knowledge. Advance notice of the questions reassured service users who might have been anxious about the questions or their ability to answer them. A General Interview Guide Approach also allows for the kind of chatty informality appropriate to the private living room or rest home lounge. The same guide was used with the focus groups to ensure that important topics were covered but at the same time allow individuals to express their point of view.

Data Analysis

Once the data had been collected an analysis matrix was created to code the data. The matrix consisted of rows for each question and columns for each of the three stakeholder groups where dominant themes and illustrative quotes were recorded.

Findings and Discussion

The meaning of recovery for older people with experience of mental illness

People with experience of mental illness and family members thought that recovery is just as important for older adults as it is for people in younger age groups.

“Recovery is relevant to older people...I am 71; I hope I’ve got productive years left”

“When my 86 year old mother got depressed for the first time I think it was not that much different than it would be for a younger person”

However, one difference did become evident. For older adults, recovery is more likely to be about regaining something of value lost through illness than it is about accepting new challenges.

“Return of mental, physical and spiritual health”

“Reclaiming or enhancing something that has been lost”

Service providers related recovery to function.

“People are well when they return to their usual activity and function in their normal environment... (for example) taking oneself to the toilet”

Definition of a peer

Both service users and family members defined a peer as someone with experience of mental illness – that a peer relationship is one of common experience.

Service users thought that to understand the vulnerability of people with mental illness a peer support worker would need personal experience of mental illness.

“They would need to know what it was like to have mental illness to understand the exhaustion and the lethargy”

And they would have to be accepting and understanding of challenging behaviour.

“I worry about the effect on my care-giver of my changing moods”

Two of the family members interviewed had personal experience of mental illness and described themselves as the peer support worker for their respective mothers because they “knew what to do”, despite the age difference.

Age differences between peer support worker and service recipient were not of concern, although some service users thought that it was important to find as close a match in age as possible.

“Peer in the sense of a contemporary – as though seeing yourself in a peering glass. My contemporary in age and experience. An exact contemporary is preferable”

Others thought that a younger person would be acceptable, perhaps even preferable, provided they had experience of life, had suffered loss or had “brought-up” a family. One clear preference was for peers of similar educational and vocational backgrounds. Service providers placed similar emphasis on the importance of socio-economic status and culture, an insight gained through observation of how friendships developed in acute units or day programmes.

Service users did not consider gender match important. Most, when asked, confessed they had not given it much thought, and prompting them to state a preference produced no consensus.

The needs of older people with experience of mental illness

Loneliness was mentioned by all stakeholders as a major problem for older adults with mental illness. Families move away, friends die and social networks diminish. As one health worker commented,

“Older people attend a lot of funerals”

For individual service users the loneliness could be acute. One rest home resident described her situation:

“My family live down the line and several of my friends have died”

And she felt that this sense of loneliness was heightened in a rest home because so many residents suffer cognitive impairment.

“It is difficult even to find four people to play scrabble”

Lack of transport, particularly in rural areas, increased isolation. Health workers explained that without their own transport many older service users missed out on day programmes because it took too long for services like St John’s ambulance to collect people from outlying areas.

Poor physical health was another problem. All stakeholders noted that poor physical health exacerbated mental illness and diminished quality of life.

“Pain is the best depressant you can have”

“I have Parkinsons and go to bed after dinner to allow my limbs to relax”

Self-stigma was another problem older adults with mental illness had to deal with. As one family member explained,

“Older people come from the era of loonies and can be demoralised by experiencing mental illness”

Ageism contributed to this feeling of demoralisation:

“Older people do not get touched”

Expectations of the role of peer support worker

The needs of older people governed expectations of the role. One common theme expressed by all stakeholders was “someone to be there”. Being there could be on the end of a phone, as a companion for coffee or lunch, as someone “to share concerns with,” or act as “a sounding board” or simply someone to talk to.

“They would be like a friend I have who is always there for me when I am down”

For participants more aware of recovery philosophy through membership in self-help organisations or as consumer advisors, “being there” meant more than a friendly drop in for a cup of tea:

“They should not stay in with the person, it just perpetuates their loneliness”

“They do not need a PSW sitting at home with them talking about mental illness and meds”

Older adult service users understood that a peer support worker offered something much more than home help.

“The home help does not have time to talk”

Many saw peer support workers as companions able to assist with what was most important at the time. A family member, feeling confident about what was needed based her own experience of mental illness, stated:

“It is necessary to do something there and then...I knew she needed to walk, just as far as the letter box...later on we went for drives, she stayed in the car, then later we went to Eden gardens”

For two service users with serious physical needs as well as experience of mental illness, tangible services such as getting the mail, assistance with personal care and providing transport were of particular importance. However, they understood that the role of peer support worker was more than instrumental support. They also wanted someone to share common interests, such as sport, and have someone with whom they could have a laugh.

Past recipients of home care services were quite specific about what a peer support worker should not do:

“They must not moan about their situation, I do not want to hear their problems”

The personal qualities required of a peer support worker

Stakeholders identified a number of ideal qualities required by peer support workers: the ability to form a collaborative relationship; ensure the durability of that relationship; and maintain safety for both parties.

A collaborative relationship, defined by the participants as one in which the person and peer support worker worked together to solve problems or set goals, is dependent on the peer support worker’s ability to engage or “get on with” with the service recipient. All stakeholder groups thought the quality of empathy was necessary for successful engagement. As one service user put it, having the support of a person who was a “source of fellow-feeling” would be “clearly beneficial”.

The quality of reliability was also mentioned. Reliability means more than “arriving on time”, it means the ability to persist, even when the going got tough. One health worker stated that a peer support worker must “want to be there”, and a service user stated

“Their work has to be as important to them as it is to me....they must not be put off easily”

Other qualities necessary to sustain a relationship are flexibility, patience and a positive attitude. Flexibility was mentioned by both providers and service users. Health workers recognised that the role of peer support worker involved

“working outside the restrained conventions of health professionals”

where the qualities of flexibility and spontaneity are an advantage. Service users saw flexibility as a willingness “to go the extra mile” and this would enable them to receive a service “beyond set routines”.

Patience, understanding and kindness were also mentioned. Service users wanted a “gentle approach”. The peer support worker would need to move at a pace appropriate to the relationship and be aware that on some days their support would not be needed. The qualities of kindness and understanding were illustrated by one service user who described how his key worker had patiently assisted him to lock up his house prior to his admission to an acute unit:

“I am not sure if he had the time but he even helped me empty the fridge and take the food to a neighbour”

A positive attitude could be demonstrated as encouragement, praise or humour

“they need to understand that older people are capable of joy and happiness”

or by helping to instil hope during the dark times:

“Those who help are the ones who love me when I am broken”

The ability to maintain boundaries was also cited as an important quality. Health workers establish boundaries to remain detached and avoid “compassion overload”. Peer support workers would face a difficult task.

“This will be a huge task and not for the faint hearted”

Service users, on the other hand, saw boundaries as a way to maintain their dignity and respect.

“The wisdom to see the boundaries which must be maintained to respect someone’s age and condition”

Additional skills

While discussing the qualities required of peer support workers, current users of mental health services for older adults were asked about the skills required in a peer support worker. Some mentioned training in communication skills. This was seen as one way to ensure that peer support workers could engage in a manner that was respectful and caring.

Other stakeholder groups, including service users who would be eligible for older adult mental health services within ten years, were much more specific on training requirements. Training in listening skills, knowledge of family dynamics and conflict resolution will be required to help enhance relationships. Peer support workers will need to understand the physical and emotional needs of older adults. They will need training to reduce risks, which might include topics such as elder abuse and being aware of changes in emotional and physical well-being. They may need training to promote cultural awareness. Health workers advocated training in the recovery approach and strengths model, as did family members who were aware of the benefits of a recovery focus. One family member described how her mother had not understood that it was possible to recover from an episode of mental illness until she had gone through the process of recovering from hip surgery. This had enabled her to draw parallels between her recovery from her physical disorder to her being in respite to assist her recovery from mental illness.

Challenges

Health workers were asked if they saw any difficulty working along side non-professionals in a consumer peer support programme for older adults. Most did not envisage problems. Many already had experience with voluntary organisations such as Age Concern visitors or Alzheimer’s Disease and Related Disorders Society (ADARDS). Some said that experience of mental illness was an important credential:

“We are the professionals but they are the experts”

The need for clear guidelines for disclosure of information related to the personal safety of either the service recipient and other involved parties was seen as one way to reduce misunderstanding between clinicians and peer support workers. The development of guidelines and the training of peer support workers was seen as the responsibility of the organisation providing the peer support service and not of mental health services.

The biggest challenge seen by health workers was “support of the supporter”. They know through their own work that older adults can be difficult to work with. Many experience negative moods, some are poor listeners and others are “fixed in their ways”. They noted that as

a group older adults are often reluctant to admit to having a mental illness and do not easily accept help. Health workers warned against the danger of peer support workers becoming “emotionally involved, as we all do”. Regular supervision was seen as essential to cope with this problem.

Respondents in all three stakeholder groups thought that recruitment might be a challenge. Many older adults might be too pre-occupied with their own deteriorating health and physical mobility to take on additional tasks. Others may be too busy enjoying life, family and leisure to devote time to providing peer support.

Potential benefits and measuring outcomes

With one exception all participants thought peer support for older adults with experience of mental illness would be beneficial. The one exception was a service user who felt that she would prefer the social support provided by her whanau.

A consumer peer support service for older adults with experience of mental illness could be expected to benefit two groups: service users who could expect an enhanced quality of life with a consequent improvement in their physical and mental health; and at a general level family members, health workers and mental health services.

Improved quality of life for recipients of a peer support service was stated in general terms such as “having a life worth living”, but also in terms more specific and measurable. These include:

- Greater independence;
- Enhanced resilience. This can mean being better able to avoid crisis through better understanding of early warning signs and better management of the illness itself from an improved understanding of mental health services;
- Improved mental health. Service users thought that this would result from “feeling comforted”, “decreased boredom” and “anxiety alleviated because know what to expect”; and
- Improved physical health. Service users thought that having a peer support worker would increase activity as opposed to “coming home just to stagnate”.

Family members felt that a successful peer support service could help reduce their burden,

“It would ease my strain, ease the pressure of caring”

Health workers expressed the hope that peer support would help reduce demands on their stretched resources, and especially the time required to provide the necessary level of emotional and social support. One staff member asked if peer support workers could be used to “back up” the key worker. Most anticipated it being a support service under less pressure to discharge people because older people take longer to respond to therapeutic intervention. Others hoped the service would offer the flexibility denied conventional mental health services.

“Old age brings changes in abilities and independence and losses...A PSW service that was on-going would enable a one-to-one relationship to be in place, ready and waiting to provide support when those changes occur”

Health workers were acutely aware that for many older adults mental health services were their only avenue of support. They gave examples such as a person becoming depressed as her discharge from a day programme became imminent, or of staff providing personal friendship following discharge. A peer support service would provide an additional level of support.

One service user gave credence to the belief that a peer support service would reduce the burden on professional mental health workers when she declared that

“I would not need my key worker who reminds me I am sick”

Evaluating outcomes

The word “difficult” inevitably found its way into any discussion of outcomes and evaluation. Stakeholders agreed that there was no easy measure. There was, however, general agreement among stakeholders that a service recipient is best placed to evaluate the effectiveness of a service. There was no consensus on how this might be done effectively. Suggestions included asking the service recipient, gauging how much the service recipient looked forward to a peer support worker’s visit or whether service recipients themselves wanted to become peer support workers. Others suggested that the best measure is an anonymous user satisfaction survey.

Professionals tended to refer to tools already available to them. One clinician used HoNOS, a tool which mainly measures changes in symptom severity, in “conversations” with service users as a way to measure quality of life. Others saw reduced use of mental health services as one measure of success in terms of “keeping people well”.

Will it work?

Service users and family members were asked if they had ever provided or received support from peers. All service users interviewed had either provided informal support or had benefited from membership in self-help groups. Some were involved in formal support networks either voluntarily (for example, through membership of GROW) or in paid work (such as being paid by mental health services to provide consumer input on service delivery). Informal support took place in a variety of settings – between neighbours, friends or between people actively engaged in mental health services.

The support provided was often quite substantive. One mother and daughter, both users of mental health services, had visited neighbours twice a day for several years to provide meals and personal care. Another service user recently discharged from an acute psychiatric unit was co-ordinating a group of past service users to lobby for improved conditions in the unit. Informal support of this nature is spontaneous and freely given by people who had been there themselves, knew what it was like and wanted to help others who were in similar situations.

“I knew what she was going through and she seemed to want to talk and I was able to understand what it was like for her”

The three family members interviewed had all provided social and emotional support to their older relative during mental illness and had been able to draw on their own expertise as a health worker or their own experience of mental illness. The support provided had filled a need but, sometimes at a cost to the well-being of the family member.

These examples illustrate that peer support among older adults with experience of mental illness already occurs on an informal basis between service users, friends, family and neighbours. Two conclusions follow from this: that peers support occurs informally and spontaneously suggests that it fulfils an innate human need for connection and experiential sharing; and that people with experience of mental illness themselves feel that peer support is important to their own recovery.

Special cultural needs

Māori

Consultation with Māori took place through a telephone interview with one older adult service user in Auckland and a focus group of tangata whairora on the West Coast of the South Island. The researchers also attended a presentation given at the Auckland Mental Health Forum on two Māori models of health: Te Whare Tapa Wha and Māori Ora Mauri Ora.

Older Adult Māori consumer views of peer support were similar to those using mainstream services.

Recovery is seen as an appropriate goal for Māori users of mental health services.

“We all need recovery, need to be able to face the world again, go out in public, do the shopping”

Qualities of a peer support worker

Apart from the obvious requirement to be Māori (*“they have to understand the culture”*), participants did not express a desire for a peer support worker of similar age or match in gender. Like Pakeha participants they felt a peer support worker would need life experience but be young enough to have a positive influence.

“You don’t want to hear about their problems, someone old could be depressing, you want someone bubbly, with some life in them”

Participants felt it was important for tangata whairora to have a choice about the gender of their peer support worker.

Participants mentioned the positive attributes of some of the health professionals they had worked with to illustrate the qualities they would like in a peer support worker.

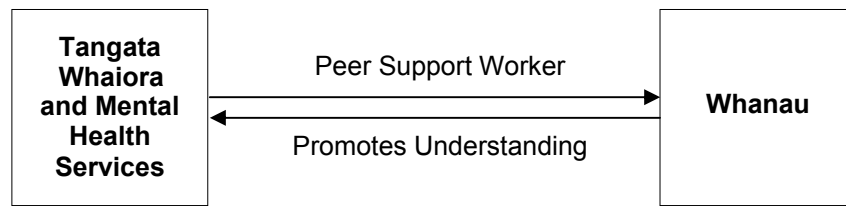
“The staff at Wai Health have them. They are there for you”

“They would need to be like the district nurse who comes to visit my husband. She knows the right thing to say to get him up out of bed – not too bossy”

Te Whare Tapa Wha, a model of Māori health devised by Mason Drurie, describes a holistic approach to health care. It is a reminder to mental health services that for Māori it is not only the mind (te hinengaro) that needs care, but also the body (te tinana) and the spirit (te wairua). The fourth “cornerstone” of this model, the family (te whanau), indicates that Māori see themselves and their well-being as inextricably tied to their whanau. Whanau are not necessarily blood relatives but those who nurture the person and provide safety. The implication is that Māori will see a peer support worker as support not only for the person experiencing an episode of mental illness but also support for the whanau.

There are at least two reasons for this. First, many Māori no longer reside in the same place as their family members. For one participant this increased her reliance on existing mental health services for support in times of crisis and for another it meant the stress of long distance travel to be with a sister coping with a rapidly progressing dementia. The grief and sorrow of not being able to support her as well as she would have liked could have been reduced by a peer support worker who would act as a link between the two sisters, as illustrated below. (See diagram 1)

Diagram 1. Peer support worker as a bridge of understanding between Tangata Whaiora, mental health services and the whanau.

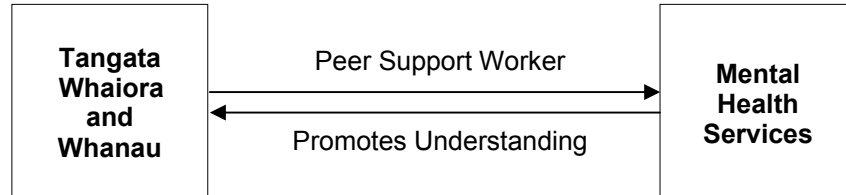


Second, participants thought that it was important for the peer support worker to have a sound knowledge both of mental illness and mental health services. Participants hoped that a peer support worker would be familiar with the various presentations of mental illness and know how to get the best out of services.

In this case the peer support worker would provide the link between mental health services, the service user and the service user’s whanau (See diagram 2). It was anticipated that the peer support worker would take the initiative in promoting the cultural values of the person and her whanau such as ensuring spiritual support was available or that there was adequate opportunity for the family to be present.

“They would know how to do it, to go out there and help...they would know the resources and contacts and what our rights are”

Diagram 2. Peer support worker as a bridge of understanding between Tangata Whaiora, whanau and mental health services.



To be an effective link the peer support worker would need to understand the particular needs and circumstances of the service user. It was suggested that this may be achieved by making provision for the peer support worker to work with the same person as they aged – the relationship could “start when they were young”. The expectation that the one peer support worker would be available over several decades may not be realistic, but a similar sense of continuity may be achieved by drawing on connections a person already has with her iwi or local marae as a source of peer support. This may reduce the possibility of “neglect” through separation from whanau members, and may help to ensure tangata whaiora were able to meet with their peer support workers in a setting they found comfortable.

The limited consultation with both mainstream and Māori service users for this project suggests one significant difference between Māori and Pakeha understandings of peer support. For Pakeha, a peer support worker is the person who walks beside the service user offering social and emotional support during their recovery. For Māori, the peer support worker provides a bridge of understanding to not only facilitate access to culturally appropriate mental health services, but also to enable the whanau to be the people who walk alongside tangata whai ora during their recovery.

Pacific people

The researchers conducted a focus group with four people of Pacific ethnicity at Lotofale (the Community Mental Health Team for Pacific Islanders in ADHB): the consumer advisor; a community support worker; a service user; and a member of her family. Key points to emerge from the focus group were:

- Recovery. For Pacific people recovery is “being able to reconnect with the family” in order to fulfil family obligations. The status of a Pacific Island person is linked to the family, “it is important that your children do well”;
- Relationship. Pacific people noted that successful relationships need time to develop. A contrast was made with the palangi or professional approach which moved to discussion of private matters very quickly and made many Pacific people uncomfortable. Pacific people stressed the importance of a peer support worker feeling “comfortable” before discussing how someone feels or enquiring after their financial state. Being “comfortable” involves taking time to share memories and stories and this is best achieved if the peer support worker and the service recipient share the same language as it “helps take the mind back”. The peer support worker for similar reasons need to be an older adult. An older Pacific Island person would be embarrassed to receive support from someone much younger unless they were a family member. Someone of a similar age would understand the need to be “graceful and forgiving”;
- Fonofale Model. For Pacific people recovery takes place within the context of home. This is symbolised by considering the fale (house). The roof represents one’s culture. It is important for individual Pacific people that their own culture and language be recognised. A peer support worker would need to be from the same island group and speak the same language as the service recipient. The foundations on which the fale stands represents the family. The four poles which support the roof are spirituality, physical health, mental health and other external influences. Being healthy involves keeping all the poles in balance; and
- There will be a number of requirements for successful peer support programme involving Pacific people. A peer support worker will need to speak the same language as the service recipient. They would be expected to build a relationship slowly and in a manner which respected the dignity and privacy of the service recipient. For example, appointments would need to be made and adhered to so that visits did not conflict with special times such as church or entertaining other family members.

Chinese

The researchers interviewed the owner/manager of a rest home catering for Chinese residents to help gain some insight into the needs of Chinese older adults. Several residents had experience of serious mental illness. The respondent explained that compared with New Zealanders of European descent, who tend to lead separate and individual lives, Chinese place a heavy emphasis on maintaining family. It was noted that not being able to care for older relatives at home and mental illness were particular sources of shame or loss of face for Chinese.

Recovery. The respondent informed us that the Chinese view of mental illness is “a bit like it was in New Zealand 50 to 60 years ago”. Chinese do not understand the concept of recovery from mental illness and believe that older adults in particular will continue to “get worse”. The stigma of mental illness makes it very difficult for older Chinese to admit openly to experience of mental illness. For this reason, a peer support service involving Chinese older adults would need to be tactful. It may, for example, be useful for a peer support worker to have experience of mental illness, but it would not be openly discussed. Instead, support of a tangible nature, such as going to the park and playing mahjong would be appreciated. The family would find it difficult to accept a relative receiving support from someone with experience of mental illness.

It may be preferable to refer to the peer support worker as a “volunteer” when meeting family.

When asked if Chinese older adults would use peer support service the answer was “possibly”, particularly if the prospective recipient lived alone. An increasing number of Chinese older adults are alone during the day while their family work, or choose to live alone because of family disputes. Despite this, the family would need to be consulted before it was acceptable to offer peer support to a Chinese older adult. It would be difficult to allow a stranger into the family. At best they would be seen as a “visitor”.

Cultural issues are also important. A peer support worker would need to speak the same language as the service recipient in order to understand cultural subtleties. If a peer support worker was unsatisfactory this would not be made clear directly. Excuses such as “My mother is too tired” would be made instead. These issues may make it difficult to gain honest feedback on perceptions of the service.

Consultation with Non-Government Organisations

The researchers interviewed Marie Hull Brown who leads the Older Peoples’ Network for the Mental Health Foundation and is chairperson of Age Concern Auckland. Marie has met many older adults during the course of her work, and much of what she said confirms our findings from discussions with the three stakeholder groups.

However, the following comments may be useful when considering the design of a peer support programme.

- The ability to empathise was seen as a more important quality for peer support workers than experience of mental illness. This is because older adults feel the stigma of mental illness to such an extent that they are reluctant to see a General Practitioner in relation to mental illness. For this reason, they would be reluctant to talk about mental health with a peer support worker. Peer support may, in fact, be more effective if it is accessible at primary care level. General Practitioners may be aware of isolated people at risk of depression. The intervention of peer support at this early stage may prevent a major depressive episode. One conclusion from this is that the service should be made widely available to older adults in the community, an idea supported by the literature on loss of social support as a factor in the incidence of depression in older adults.
- It is possible that health professionals may challenge the service. They may not respect volunteers and Marie suggested that co-ordination by a health professional may be required to alleviate mistrust. A health professional would also be better trained to detect any deterioration in health.
- Another challenge to the service may come from family members worried that a peer support worker could undermine their own role as listener and confidant.
- Peer support workers would need to be aware of elder abuse and where to refer the service recipient should they wish to report it:

“Mental abuse and being deprived of money are more common than physical abuse, difficult as older people are loyal to their family and would not report money stolen”

The researchers also interviewed Anthea Palmer, the Regional Co-ordinator of the Accredited Visiting Service (AVS) for Age Concern Auckland. AVS runs a visiting service aimed at reducing isolation and loneliness among older adults living both within the community and in residential care. The project team were interested in whether an existing Non-Government Organisation was capable of adapting its current service to provide peer support for older adults with experience of mental illness.

The visiting service could not readily be adapted to a peer support service for older adults with experience of mental illness for two reasons: 1) visitors are not peers. The visiting service's definition of "peer" is so broad as to encompass all volunteers simply because they are non-professionals. The visiting service draws extensively from the retired population for its volunteers, but people of any age can be accepted as visitors; and 2) there is no explicit intention to provide a service to people with experience of mental illness, although Anthea was able to give us anecdotal evidence of people with experience of depression benefiting from the service. Experience of mental illness does not disqualify a person from receiving a visitor, but the five hour orientation and training programme would not sufficiently prepare volunteers to support a person through a crisis. Volunteers receive no training on awareness of changes in mental health status. There is an absence of supervision apart from a requirement to report to the co-ordinator once a month. The visiting service does, however, provide support for people with early-stage dementia and information is requested on the client information form regarding cognitive status. The initial training package does address the difficulties sometimes encountered in trying to engage with people with cognitive impairments in a 30 minute session entitled "Communicating in difficult situations".

In its present form, Age Concern's visiting service would not be able to provide a comprehensive peer support service for older adults with experience of mental illness. However there is a need for social support of older adults with dementia (see below), and with adequate training and supervision AVS may be able to provide this specialised support.

Peer support for people with dementia

Our interviews with the health worker stakeholder group exposed opposition to any attempt to exclude people with early-stage dementia from a peer support service. The literature and comments by mental health service providers confirms this opposition. It was stated that any attempt to separate early-stage dementia from mental illness would be an "artificial separation" and discriminatory.

"This is discriminatory, the scenario of being depressed prior to developing dementia is a real one...What are you going to do – suddenly stop PSW service when MMSE drops below 24?"

"Not having this service available for people with dementia creates a barrier, after all dementia and mental illness are both happening in the brain. People with dementia can become psychotic or depressed. It is like saying we will treat people with cancer but not people with AIDS"

Regional variations were apparent in policies towards people with dementia in mental health services for older adults. ADHB accepts people who show symptoms of dementia before they are 65 years of age ("early-onset dementia") if there are behavioural problems and in order to establish the diagnosis. However, as one social worker explained, it is difficult in practice to comply with rigid criteria:

"As regards dementia we see a lot of people with dementia even though officially we are not supposed to. It is difficult because often depression goes with dementia"

The Bay of Plenty District Health Board has a different set of criteria.

"MHSOP see older people with dementia if there is a problem with behaviour because the Elderly Team do not provide a community service"

Family was another reason to include people with dementia in a peer support service. One senior nurse explained that

"The family are very distressed when a diagnosis of dementia is given"

Family members felt that access to a peer support service would help relieve some of the pressure they felt to provide social support.

To deprive a group of older adults of a potentially therapeutic intervention on the grounds of cognitive impairment was seen to reinforce ageist discrimination against older adults.

“This exclusion reinforces society’s ideas about the usefulness (and) uselessness of older people”

Findings and Recommendations

Findings

- A consumer peer support service for older adults with experience of mental illness is needed. All stakeholders consulted pointed out that older adults with experience of mental illness are neglected relative to other service user groups, and all stakeholder groups agreed that a formal peer support service for older adults is long overdue. The project team found evidence of peer support networks already in existence informally within both the community and in units which suggests that older adult service users themselves believe that peer support is beneficial and needed.
- The literature review found very little specifically related to older adults and peer support. This confirms our suspicion that researchers, traditional mental health services and consumer groups have neglected the particular needs of older adults with experience of mental illness. The literature did confirm that older adults are receptive to recovery focused services and that peer support may be of particular benefit to older adults through the sense of meaning and control provided through the giving and receiving of support.
- Stakeholders hoped that a peer support service for older adults with mental illness would allow a degree of instrumental support in addition to its primary focus on providing emotional support. Peer support is more than turning up for a cup of tea and a chat about mental illness. Some stakeholders suggested that such a limited approach would only serve to perpetuate isolation. Instrumental support in this sense does not mean cleaning the house, it means involving a person in the outside world which may mean taking them out to a film or community event.
- The personal qualities required in a peer support worker are those that foster a collaborative, durable and safe relationship. Service users need to be respected as equals by peer support workers honestly committed to their task. Kindness, patience and understanding are qualities demonstrated by a peer support worker's willingness to persist with the job despite obstacles, to work outside the usual routines of health professionals and to allow the recipient of the service to lead the relationship.
- Service providers will need to be educated about the new service. The literature suggests that innovative services such as peer support will most likely fail if existing services are not informed of their existence, are not educated about their purpose or do not know how to utilise the service. The literature also suggests that new services need significant time to develop their identity and become accepted by traditional services.
- Ethics and boundary issues emerged as important factors in both the literature and in consultation with stakeholders. Peer support workers are non-professionals and there will be an inevitable blurring of boundaries with the service users they support. This is of concern to existing service providers. To overcome this peer support workers will need training in health care ethics grounded in the recovery philosophy. Regular supervision will be required to ensure that peer support workers operate in a safe, effective and ethical manner.

Recommendations

- Autonomy from existing services. A peer support service for older adults should be autonomous from existing mental health services for several reasons. Peer support offers a dimension of support quite separate from clinical services. There is a risk that a peer support service too closely integrated within existing services could become professionalised or co-opted into services and thus lose the unique quality of peer support.

- Volunteer rather than paid peer support workers. Older adult peer support workers will need to be volunteers for several reasons. Most will be over retirement age, may have other interests they wish to pursue in their retirement, and may not physically be able to commit to the regularity and responsibility of paid employment. Unlike younger age groups, older adult peer support workers do not see peer support as a potential career path.
- The service should be integrated within an existing Non-Government Organisation. Some Non-Government Organisations such as Age Concern have considerable experience in working with older adults volunteers. The project team did discuss the issue of contracting the service with Age Concern, which receives funding from the government for the national accredited visiting service. One benefit of using Age Concern is its national infrastructure, which could be adapted to include a peer support service for older adults with experience of mental illness. However, there are also problems. Age Concern has no experience or expertise in providing services to people with experience of mental illness, and its current selection criteria, training and supervision policies are inadequate.
- Intensive training and supervision. The literature suggests that training requirements for a peer support service for older adults will need to be intensive, perhaps of greater duration than training for younger adults and especially adapted to the needs of training older adults. Older adults often lack confidence and this will take time to overcome. Older adults will need training in listening skills, how to be non-judgemental and how to resist the urge to give advice. Intensive supervision will be required. One study suggests that initially as much as one hour of supervision for every four hours spent with service recipients.
- Make the peer support service available at primary care level. This recommendation is the result of consultation with a Non-Government Organisation. Peer support may be especially useful if it is accessible at primary care level. General Practitioners may be aware of isolated people at risk of depression, and peer support could play a useful preventive role.
- Include people with early-stage dementia. This recommendation is beyond the remit of the project description which specifically excludes people with dementia. However, in the course of the consultation with stakeholders it became apparent that there is significant opposition to the exclusion of people with early-stage dementia from any future peer support service. Many felt that to separate early-stage dementia from mental illness was to create an artificial separation given the close relationship in symptoms. They argued that such a separation would be unfair to the families of people diagnosed with dementia. Furthermore, to deprive older adults of a potentially therapeutic intervention on the grounds of cognitive function is discriminatory and will reinforce ageist stereotypes.
- Outcomes. Measure outcomes by regular review of personal plans to determine if set goals are being achieved. Survey service users through the use of anonymous satisfaction surveys to determine if the service is recovery focused. To keep it simple the project team recommend using the strengths model of service delivery and measure the achievement of goals set by the service users. Anonymous service user satisfaction surveys are one way of gauging the opinion of the most important stakeholder group – the recipients of the service.

See Appendix B for guidelines for a model of a peer support service for older adults with experience of mental illness.

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Appendix A

Questions for Service Users

- What are the characteristics of a “peer” in the context of supporting an older person who experiences mental illness?
- What are the special needs of the older person with experience of mental illness?
- Do you have any personal experience of being a peer support worker, being the recipient of peer support or being a member of a self-help group?
- If you were offered the services of a peer support worker what would you want them to do?
- What qualities would you expect that peer support worker to possess (e.g., age, gender congruency, attitude, skills etc.)?
- What sort of outcome/benefit would you be looking for if you were to use such a service and how would you evaluate it?
- Do you know of other older people who have used services who may be willing to join a focus group?

Questions for Providers

- How would you define a “peer”?
- What do you see as the benefits/challenges of involving peers as supporters of older people with experience of mental illness?

If a service existed you may be the people referring clients to the peer support service. What would your expectations of that service be in terms of:

- Characteristics you would expect peer support workers to possess both in terms of personal qualities and qualifications?
- Training the peer support workers had received prior to beginning work?
- In service training available to peer support workers?
- Relationship of peer support workers to professional workers?
- Job description – what would you expect them to do?
- Outcomes – what would incline you to continue referring clients to the service?
- Do you have any fears/anxieties as a health professional referring clients to “non-professionals”?
- Would your service need to change in any way to adapt to this additional service for your clients?
- Can you suggest anyone else we should be speaking to regarding peer support for older people?

Questions for Family Members

- What are the characteristics of a “peer” in the context of being able to support older people with experience of mental illness?
- What are the special needs of the older person with experience of mental illness?

- If you were offered the services of a peer support worker for your family member what would you want them to do?
- What qualities would you expect that peer support worker to possess (e.g., age, gender congruency, attitude, skills etc.)?
- If a peer support worker were to work with your family member what sort of training would you expect them to have undergone?
- What sort of outcome would you be looking for if your family member were to use such a service and how would you evaluate it?
- Have you, or your family member, experienced any support from peers or self-help groups?
- Do you know of any other person in your situation, supporting an older family member who experiences mental illness, who would be happy to be interviewed for this project?

Appendix B

Draft Service Provision Framework

Peer Support for Older Adults with Experience of Mental Illness

The Vision: To promote the recovery of older adults with experience of mental illness by offering social support delivered by their peers.

The Service Provision Framework: The SPF outlines the strategy for implementing the vision. It includes the structures, policies and procedures which underpin the proposed peer support service for older adults.

This draft is a guide only. It is up to the people who provide the service to work together to provide the detail of the structures, policies and procedures. The Service Provision Framework represents an evolving document, which aims to provide a clear and consistent approach to service provision. The Service Provision Framework aims to promote ethical, effective and efficient service delivery, consistent with Mental Health and Health and Disability Standards, for which all staff are accountable.

The Service Provision Framework consists of:

1. Service focus – a description of the service and tasks;
2. Service processes – information on accessing, entering, engaging with and exiting from the service;
3. Interfaces – defines the responsibilities of the service and its relationship with existing mental health services (both District Health Boards and Non-Government Organisations);
4. Service functioning – Policies on training, supervision and caseload management;
5. Job descriptions – defines the specific tasks undertaken by each role; and
6. Self audit tools – outlines the process for regular review of staff performance.

1. Service focus

Description: The service offers peer support to older adults with experience of mental illness.

Tasks:

1. Assists and encourages people to recognise their strengths;
2. Supports people to develop clear, achievable goals; and
3. Supports people to access and use resources in the community.

2. Processes

This section outlines how older adults can access the service, engage with it, progress through the service and end contact with the service.

Service Access Process

Process	Tasks	Who
Person themselves or family member contact OAPSS (Information about the service is available in Mental Health Units, General Practitioner waiting rooms)	1. Person's contact details taken 2. Details passed onto team leader 3. First meeting to ascertain person's understanding of service arranged	1. and 2. Staff member at OAPSS who answers the call 3. Team leader

Engagement with Service

Process	Tasks	Who
1. Ascertains person understands the type of support offered by the service and consents to engage with the service	1. Explains aims and processes of service	1. Team leader
2. Match to peer support worker	2. Records personal preferences of the person, discusses profile of potential peer support worker and contacts peer support worker	2. Team leader
3. Arrange first meeting	3. Set time and place	3. Peer support worker and person

The Peer Support Process

Process	Tasks	Who
1. First meeting with peer support worker	1. Build rapport and confirm willingness of person to work with assigned peer support worker	1. Peer support worker and person
2. Subsequent meetings	2. Set goals and regularly review	2. Peer support worker and person

End of Contact

Process	Tasks	Who
1. Person or peer support worker raises topic based on regular review of goals (achieved or not achieved)	1. Discussion around leaving the service	1. Peer support worker and person
2. Check-in and review	2. Review check list (e.g., WRAP in place, goals achieved, supports in place)	2. Peer support worker and person

3. Interfaces

This section defines the major interfaces of the Older Adult Peer Support service with existing Mental Health Services. It aims to locate the boundaries of each interface and specify how they will be managed in terms of information (both given and received) and clinical responsibility.

Sample Guidelines:

- The Peer Support Service takes no clinical responsibility for the people who use the service;
- Self-referral from older people with experience of mental illness who wish to work with a peer support worker is the preferred mode of access to the service. Referrals may be accepted from family members once it has been established that the person who will use the service approves of this process;
- Referrals will not be accepted from mental health workers;
- The Peer Support Service will record only the information the person chooses to divulge; and
- The Peer Support Service will liaise with Mental Health Services only at the request of the person using the service or if the person is in imminent danger of harming themselves or others.

4. Service functioning

This section includes policies and procedures, which govern the day-to-day operation of the service.

Sample of the policies to be included in this section:

1. Work load management –
 - Defines the service's expectations of maximum workload
 - Describes how the service tracks workload numbers;
2. Training –
 - Defines the goals of initial training
 - Specifies content of initial training programme (e.g., Recovery Approach, Strengths Model and how to apply it to older adults, special needs of the older person, how to access community resources, listening skills, Treaty of Waitangi)

- Defines the goal of continuing education/professional development
 - Specifies the service's expectations of staff to participate in on-going training; and
3. Supervision –
- The purpose of supervision (e.g., to ensure peer support workers work in a safe, ethical and effective manner)
 - Defines types of supervision (e.g., group supervision, peer supervision, individual supervision, personal supervision)
 - Specifies the service's expectations of staff to participate in supervision (e.g., Outlines the duration and frequency of supervision sessions and the preparation required by staff prior to attending each session).

5. Role descriptions

Sample role description for Peer Support Worker.

Purpose

To respect and promote the autonomy of people using the Peer Service Worker Service through engaging in a relationship that acknowledges and builds on their personal strengths.

Key Accountabilities

1. To ensure the people using the Peer Service Worker Service are supported to achieve their chosen goals.
 - Works in partnership with the person using the Strengths Assessment to help the person to identify current and past resources.
 - Encourages the person to identify their wants/desires as basis for goal planning.
 - Assist the person to develop a written plan for the achievement of SMART short- and long-term goals.
 - Assists the person to achieve goals through supportive actions, education, problem solving, role modelling or experiential practicing/role playing in natural settings.
 - Assists the person to identify and obtain naturally occurring community resources that will help them achieve their goals and objectives.
 - Regularly reviews and evaluates goal achievement with the person.

2. To assist the person to identify obstacles to achieving goals as well as the strengths they possess and the resources available to develop resilience.
 - Supports people to create a Wellness Recovery Action Plan (WRAP).
 - Encourages people to keep and maintain their own file (including their WRAP, advanced directives, strengths assessments, etc.), and to bring it to each Peer Support contact/meeting.
 - Provides people with information regarding relevant legislation, rights and responsibilities.
 - Supports the person to advocate for themselves in the community and mental health system for the purpose of helping them to access and use desired resources.

3. To participate in meetings designed to support peer support worker team members and the development of the Peer Support Worker Service.
 - Attends and participates in service meetings to ensure effective communication and brain-storming to get the wants and needs of people met.
 - Attends and participates in group supervision and one to one supervision (Group Supervision is the primary mode of supervision).
 - Maintains good self care practices and takes responsibility for monitoring wellness (Advanced Directives in place).
 - Complete paperwork in a timely manner including: Timesheets, Strengths Assessments, Goal Plans and any required reports.
 - Employs a variety of learning modalities (e.g., workshops, reading, requesting and using feedback, asking questions) in the quest to grow.
4. To work in a manner consistent with New Zealand's commitment to biculturalism and Te Tiriti o Waitangi.
 - Understands the significance of the Treaty of Waitangi and applies these principles to work practice.
 - Meets with people who offer cultural support at the person's request.
5. Participates in quality improvement.
 - Works with the peer support worker team to ensure the Peer Support Worker Service complies with Mental Health and Health and Disability standards.
 - Participates in continuous quality improvement.

6. Self audit tools

Regular performance reviews allow the service to:

- Recognise individual skills and contributions to the organisation;
- Note deficiencies in performance;
- Provide training opportunities; and
- Provide targeted support.

This section specifies:

- The frequency of performance reviews for individual peer support workers (e.g., six monthly);
- The frequency of performance reviews of the peer support team as a whole (e.g., annually); and
- The frequency of reviews of goals set by the person using the service (e.g., three monthly).

This section also outlines the tools used in each of the performance reviews. A sample is shown below.

Quality Review of Peer Support Worker Performance

PSW Reviewer

Date Score

**2 = full achievement, 1 = partial achievement,
0 = no evidence of achievement**

1. Attends and actively participates in service and organisation meetings to ensure effective communication and brainstorming to get the wants and needs of older adults met. (*Attends staff meetings, forums, special meetings.*)

0 1 2

2. Attends and actively participates in group supervision. (*Obtain from record of attendance.*)

0 1 2

3. Assists people to identify their wants/desires and to write them as goals with small, measurable, realistic steps. (*Evidence in goal plans.*)

0 1 2

4. Addresses, reviews and/or evaluates goals and objectives with the person on a regular basis. (*Evidence of frequent goal review in Personal Plans.*)

0 1 2

5. Assists people in identifying/obtaining resources by linking them to desired resources. (*Evidence of this in goal plans.*)

0 1 2

6. Assists people in achievement of goals through supportive actions, education, problem-solving, role modelling and experiential practicing in natural settings. (*Can illustrate examples of this behaviour.*)

0 1 2

7. Assists people in planning for maintenance of wellness and identifying preferred actions to be taken at times of relapse (*WRAP plans developed.*)

0 1 2

8. Completes paperwork in a timely manner including: Timesheets, Strengths Assessments, Goal Plans, Person Status Reports, and any required reports.

0 1 2

9. Growth and development is evidenced by curiosity and a quest for learning. (*Is engaged in the pursuit of learning opportunities.*)

0 1 2

10. Utilises the Service Provision Framework. (*Follows procedures outlined in SPF during day to day delivery of service.*)

0 1 2