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Evidence Check

The effectiveness of services led or run by consumers in mental health

An **Evidence Check** rapid review brokered by the Sax Institute for the Mental Health Commission of New South Wales.

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The effectiveness of services led or run by consumers in mental health: rapid review of evidence for recovery-oriented outcomes

Contents

1 Executive summary

There is a small but steadily growing number of research studies showing that services controlled and run by people with lived experience of mental illness ("Consumer-operated services") are effective in supporting recovery. Such services tend to be characterized by consumer control, choice, voluntary participation and opportunities for decision-making by consumers (Holter et al 2004).

Most of the evidence for the effectiveness of consumer-operated services comes from the United States, where three large studies have each published multiple papers on their findings. The largest, the "Consumer Operated Services Program" (COSP) study (see Clay et al 2005) examined eight consumer-operated services and compared the recovery outcomes of people who used these services with people who only used traditional services. They found that people who accessed consumer-operated services experienced improved levels of empowerment, social inclusion, well-being, housing, employment, hope and program satisfaction, than those who accessed only traditional services. There were, however, significant differences between results from the different COS programs. Another study (see Nelson et al 2006) compared a range of recovery measures for participants in four consumer-run organisations, over three years, with participants who did not access consumer-run organisations. They found that participants in the consumer-run organisations had small increases in quality of life, spent fewer days in psychiatric hospitals, used emergency services less, participated more in employment and education, had more stable mental health, enhanced social support and more stable income, when compared with people who did not access these organisations. They also found that these results continued after three years. The third study (see Segal et al 2013b) examined what qualities of consumer-operated services led to improved recovery outcomes. They consistently found positive results for consumer-operated services, with the exception of one hierarchically-structured organization. It is not, however, possible to generalize from this one study. A large number of smaller studies, including research looking at peer-run respites as alternatives to psychiatric hospitalization (e.g. Croft and İsvan 2013) also showed promising results.

There is not enough evidence to say how these results relate to members of population subgroups, such as people living in rural and remote settings, members of Culturally and linguistically diverse (CALD) communities, Aboriginal and Torres Strait Islander people, and lesbian, gay, bisexual and transgender (LGBT) people. What evidence there is points to the possibility that some people may prefer to seek treatment from culture-specific organisations, rather than mental health organisations. It is also important that the staff working in consumer-operated services reflect the population of people who use the service.

Recommendations of this report include the commissioning of a survey of consumer-operated services in Australia (similar to two conducted in the United States – Goldstrom et al 2006 and Ostrow et al 2014), to find out what is currently happening. Evaluation of existing services is also encouraged, with an emphasis on the kinds of outcomes that are meaningful to consumers. This will mean that consumers need to be involved in the research processes. Finally, it is also important that consumer-operated services that are particularly successful be encouraged to document what it is that they are doing well, to share their success stories and inspire others.

2 Background and introduction

While people with lived experience of mental illness have long been offering informal support to each other – probably wherever they have been brought together – it is only since the 1970s that such support has become more formalised and organised, leading to the emergence of various consumer-run services, especially in the United States (SAMHSA 2011; Nelson et al 2006, 2007; Clay et al 2005). There is a strong emphasis on peer-support in the UK, but much less of an emphasis on peer-run organisations, aside from peer-run self-help groups (Faulkner et al 2013; Faulkner and Kalathil 2012). In Australia, no survey has been conducted of peer-run organisations. Queensland has the most developed approach: the Consumer-Operated Services (COS) program, which was evaluated in 2013 (Australian Healthcare Associates 2013).

Holter et al (2004) surveyed national experts on consumer-run organisations in the US and found that consumer control, consumer choice, voluntary participation (the absence of coercion), opportunities for decision-making and respect for members by staff were considered critical elements of consumer-run services. Mead et al (2001) describe 'a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful.' Solomon (2004) points to social support and experiential knowledge as key ingredients. More recently, based on a survey of 380 consumer-run organisations in the US, Ostrow and Leaf (2014) identified the elements of 'empowerment, self-direction, and mutual relationships.'

While there is relatively broad agreement about values, there is no consistent *language* used in the literature to refer to services controlled or delivered by people with a lived experience of mental illness. A variety of terms are used, and these terms are used inconsistently across the literature, to refer to a variety of roles and service structures. In this report, the terms "peer" and "consumer" are used interchangeably, reflecting their widespread use. While a great deal of work has been undertaken to describe the different roles that peer/consumer workers may engage in, and the different environments they might work in (e.g. HWA 2013), this is an environment characterized by considerable variation and ongoing change. The National Mental Health Consumer/Survivor Self-Help Clearinghouse uses the language of "Consumer Directed Services" (www.mhselfhelp.org); Goldstrom et al (2006), in their 2002 national US survey, differentiated between mutual support groups (MSG), self-help organisations (SHO, which included advocacy organisations) and consumer-operated services (COS), although they – confusingly – included carer groups and organisations, undifferentiated from consumer groups and organisations. Ostrow and Leaf (2014) use the terms "consumer-operated service programs," "peer-run organizations" and "Mental health peer-controlled services" interchangeably in the space of just one paragraph. The literature is replete with research studies that have invented new acronyms to describe their object of study, including: CSI - Consumer-Survivor Initiatives (Nelson and colleagues 2006); CRA - Consumer-run agencies (Hodges 2006); CLMH - Consumer-Led Mental Health services (Doughty and Tse 2011); and BSR-COSP - Board-and-staff-run Consumer-Operated Service Programs (Segal et al 2013a). Various definitions or inclusion criteria have also been suggested: SAMHSA's (2011) report on Consumer-Operated Services offers the definition: 'a peer-run program or service that is administratively controlled and operated by the mental health consumers and emphasizes self-help as its operational approach,' where administrative control is defined as a minimum of 51% of consumers on the board, and a consumer director. Ostrow and Leaf (2014) offer this definition:

> Peer-run organizations are defined as "programs, businesses, or services controlled and operated by people who have received mental health services," with the mission of using support, education, and

advocacy to promote wellness, empowerment, and recovery for individuals with mental disorders. (Ostrow and Leaf 2014:239)

They outline the following criteria, developed by a five-member panel of consumer advocates, technical assistance providers, program directors and researchers: an incorporated, independent nonprofit organization or a nonincorporated organization that operates independently from a parent organization; at least 51% of the board of directors or advisory board are peers; the director is a peer; and most staff members or volunteers are peers (2014:240). They stress that any definition must emerge from consumers. It is not clear, however, what constitutes "independence" or "most staff or volunteers."

While recognising the diversity of language and inclusion criteria used across the literature, this report has opted to use the language of Consumer-Operated Services (COS), following Australian Healthcare Associates (2013), Ahmed (2013), SAMHSA (2011) and Clay et al (2005). The distinction suggested in the project brief between "consumer-run" services (ie. organisations run by and for mental health consumers) and "consumer led" services (i.e. services staffed by consumers, but with governance structures or oversight involving non-consumers) is not supported by the literature (except in passing in Doughty and Tse 2011). In fact, this language may cause confusion with another distinction made in the literature: between *consumer leadership* as an emerging paradigm that contrasts with the older *consumer representation* paradigm (Gordon 2005, Happell and Roper 2006, Victorian Government Department of Human Services 2007). Because the language used in the literature is so diverse, this report does not consistently impose the term "Consumer-Operated Service" onto research studies where this may not accurately reflect the nature of the organisations being studied.

One way of conceptualising differences in degree of consumer control is offered by the Consumer Involvement Station (2014) at the University of Melbourne. Drawing on Arnstein's ladder - a well-known tool for analysing different models of participation - a distinction is drawn between contexts that are:

- *Consumer-controlled*: where a service or project is initiated and run by mental health consumers (e.g. a consumer-run advocacy program);

- *Delegated power:* where space is created within non-consumer-controlled environments and offered to consumers to control (e.g. a peer-run support group on an acute unit);

- *Partnership*: where consumers and non-consumers collaboratively create, design and implement a service or project (e.g. education courses co-designed within a Recovery College).

These three contexts are all identified as involving consumer power, albeit with different structural relationships to sharing power with non-consumers. These three are contrasted with forms of consumer participation in which consumers lack control: these may either be *tokenistic* or worse. One particularly pernicious pattern Arnstein describes as "*therapeutic*" forms of participation, where there is a pretense of valuing consumer contributions, accompanied by an implicit agenda to be therapeutic for the consumer service-providers. Such approaches are dishonest and disrespectful of the contributions made by consumers. Another is contexts Arnstein describes as "*manipulative*", where consumers are provided with a script/formula, which has been created by others. Unfortunately, there are many examples in the literature of consumer workers being in contexts that Arnstein would describe as "therapeutic" or "manipulative" - an example of the latter is contexts where a consumer role is intended to "improve consumer cooperation with nursing staff" or "improve engagement with the mental health service" (both examples are from Nestor and Galletly 2008:346). While Arnstein's language (especially the term "delegated power") may be of limited usefulness, the distinctions she draws may be useful.

However, as Goldstrom et al (2006) note, these groups 'exist on a continuum with amorphous boundaries.' The Hearing Voices movement in Australia clearly demonstrates this fluidity. The national Hearing Voices Network Australia (HVNA) is auspiced by Richmond Fellowship WA (http://hvna.net.au) and brings together voice hearers, professionals and family members: this suggests HVNA can be understood as a *partnership*, according to Arnstein's typology. However, a group within this network, Voices Vic, self-describes variously as being 'led by people with a lived experience' (www.prahranmission.org.au/ourservices/voices-vic/#page_1) and as 'a network of professionals, carers and voice hearers' (www.prahranmission.org.au/ourservices/voices-vic/#page_2). Like HVNA, Voices Vic has a relationship with a community mental health organization, Prahran Mission, but it is not clear whether this relationship would be best described as delegated power or partnership. In 2011, Voices Vic was jointly awarded a Gold Award at The Mental Health Services conference in the "Consumer-Provided Services" category (www.themhs.org/award_archive.php?type=1&year=2012), suggesting that Voices Vic is making a valuable contribution and could be characterized as in some sense "consumer-provided." This current review did not need to come to any conclusions on this issue since, while Voices Vic is actively researching its approach, there is currently insufficient research to determine its effectiveness (Voices Vic 2009). This is arguably an area of increasing interest, accompanied by increased research activity, suggesting that further work is needed to articulate what constitutes a consumer-operated service, and when and why such distinctions are important in the Australian context.

Excluded from scope were materials that discussed consumer work roles that did not involve direct support (e.g. in education of the non-consumer workforce, research, service planning, evaluation or quality improvement roles). While these roles undoubtedly impact on recovery-oriented outcomes for consumers, by contributing to creating a workforce and service environments that are more conducive to recovery, the outcomes of such work have not been evaluated for their impact on recovery-oriented outcomes for service users. This is not to discount the critical importance of such work. In fact, some of the observations about enablers and barriers in this report would suggest that education of the non-consumer workforce, for example, has a particularly important role to play in enabling the work of consumers who provide direct support.

Distinctions between services (and roles) that provide direct support and those that do not are not necessarily clear-cut, however. Ostrow and Leaf (2014) distinguish between organisations that provide direct peer support and those that are primarily technical assistance or advocacy centres. Examples of the former might include the National Empowerment Centre in the US and Our Consumer Place in Victoria; examples of the latter might include Advocacy Unlimited in the US (see Clay 2005) and Being: Mental Health & Wellbeing Consumer Advisory Group in NSW. However, as Clay et al (2005) explore in the context of Advocacy Unlimited, in the contemporary recovery environment, clear-cut distinctions between education, information provision, advocacy and "support" are not necessarily always possible or even useful: for some people, participation in advocacy may be an empowering part of their recovery journey. The emergence of Recovery Colleges in the US, UK and, more recently Australia, offers another example of the diversification of the recovery environment, beyond services conceptualised as offering predominantly "support." As the roles and environments in which consumers work diversify, it is becoming increasingly difficult to determine what kinds of services should be considered within the scope of a review such as this.

3 Analysis of the literature

Review question 1: "For mental health services that are or include components which are consumer run and/or consumer led, what is the evidence base for effectiveness with respect to recovery-oriented outcomes?"

There is a small but growing body of evidence that demonstrates the effectiveness of consumer-operated services with respect to recovery-oriented outcomes. The evidence base is relatively small and there are no meta-analyses of this evidence, but the results are consistently positive across a number of measures.

The strongest evidence comes from a small number of large-scale studies:

- The multi-site Consumer-Operated Services Program (COSP) study in the US (Rogers et al 2007, Campbell 2006, Clay et al 2005) involved eight consumer-operated services and ran over several years. Their results demonstrated that involvement in consumer-operated services had positive impacts on levels of empowerment, social inclusion, well-being, housing, employment, hope, recovery and program satisfaction.

- A series of studies by Segal and colleagues (including Segal et al 2002, 2010, 2011, 2013a, 2013b) has sought to understand what elements make consumer-operated services empowering. They consistently found positive results for consumer-operated services, including increased independent social functioning and personal empowerment.

- A series of studies by Nelson, Ochaka and colleagues (including Nelson et al 2006a, Nelson et al 2006b), examining participation in four consumer-operated services. Again they consistently found positive results, including reduced costs (when compared with traditional service usage), increased quality of life, increased level of functioning, reduced psychiatric symptoms, reduced use of psychiatric services, increased treatment satisfaction, greater participation in employment or education; more stable mental health and enhanced social support. Significantly, these results continued after 3 years.

A number of other, smaller studies also found a range of benefits, including social functioning (Yanos et al 2001, Segal et al 2002), personal empowerment (Segal et al 2002), hope and self-efficacy (Hodges et al 2008), quality of life (Bologna et al 2011), self-determination and self-awareness, advocacy, medication-related decision-making and meaningful engagement with traditional providers (Jones et al 2013), reduced use of emergency and inpatient services (Croft et al 2013), and reduced costs, increased level of functioning, reduction in psychiatric symptoms and increase in treatment satisfaction (Greenfield et al 2008).

This review also posed a number of sub-questions:

Sub-question (a): What does "effectiveness" look like? Ie. How have recovery-oriented outcomes been measured and what sorts of effects (benefits) have been reported?

A number of different measures may be considered as markers of "effectiveness". While the most relevant to this review are the effects on service-users (discussed above), this review also considers as relevant:

- the effects on consumer service-providers;

- the effects on mental health services;

- fidelity to consumer philosophies (ie. guarding against both tokenism and co-optation);

- cost-effectiveness.

While these measures are only indirectly relevant to the key question in this review, it is suggested that a service that is effective in providing results for service users, but at the expense of the consumer service-providers or by co-opting consumer workers into inauthentic ways of working, can hardly be viewed as genuinely "effective." Similarly, it is inappropriate to laud the cost-effectiveness of consumer-provided services if this is predicated on the exploitation of consumer workers: while consumers have as much right as others do to volunteer their time and skills to organisations, fair remuneration for consumer workers needs to be given serious consideration – all too often, consumers workers are treated as "paraprofessionals" and unpaid or underpaid (Watson 2013).

There are complex relationships between these factors. In the context of the impact on consumer service-providers, it is important to neither over-emphasise nor under-emphasise the benefits to the consumer workers themselves. A variety of findings have suggested that peer work offers recovery benefits to the individual consumer workers (e.g. Salzer et al 2013, Biedrzycki 2008, Rapp et al, 2008, McDiarmid et al 2005), while other studies have suggested, to the contrary, that peer work comes at a high cost (e.g. Byrnes 2013, Bennetts et al 2013). It is also important to bear in mind that peer workers need to be recruited because they can do the specific job (Carlson et al 2001, Chinman et al 2006, Orwin 2008), not just for their own recovery outcomes. As one provider, quoted in Orwin et al says 'a special recipe for disaster is the belief that you should employ someone because you think it will do them good. It's also important to be clear about what is being studied – for example, some studies have conflated the outcomes for service users and the outcomes for (peer) service providers, measuring the "impact" of peer work in how it affects the recovery journeys of the peer support providers. This treats peer support workers as if they are themselves service users, rather than service providers (and is an example of what Arnstein would denounce as "therapeutic" participation, see discussion earlier), which can potentially devalue the contribution and work of consumer providers and their capacity to positively influence the recovery journeys of others. However, the differentiation between support-provider and support-recipient should also not be overly reified, given that one of the qualities of peer support emphasised in the literature is mutuality - the capacity for consumers to both give and receive support.

In terms of fidelity to consumer philosophies, there is a strong tendency for peer-reviewed articles to be written by non-consumer professionals (Doughty and Tse 2011:264, an observation also borne out by the data-collection for this study - see Appendix B). Research studies may thus not be grounded in consumer philosophical principles. For example, Gomez (2013) studied Certified Peer Support Specialists, using two outcomes as measures of effectiveness: inpatient psychiatric hospital admissions and treatment adherence in regards to professional appointments kept - it is quite striking that such a recent study could ignore contemporary recovery-orientation.

Hardiman et al (2005) note that evidence based practice tends to require 'standardised and structured' interventions, whereas consumer-run organisations often offer highly individualised, unstructured support. Faulkner and Kalathil (2012) argue that: 'It would be almost impossible and perhaps also undesirable to conduct a conventional randomised controlled trial of the benefits of being a member of a peer support group.' Thus, it is suggested, research methods that are able to remain faithful to peer philosophies should be considered.

In terms of cost-effectiveness, a number of studies have demonstrated that consumer-run services are cost-effective (Dumont et al 2002, Greenfield et al 2008, Doughty et al 2011, Yates et al 2011, Trachtenberg et al 2013). However, cost-effectiveness must also be considered in conjunction with the other markers of success - for example, a service could hardly be described as "successful" if its cost-effectiveness is

predicated on the underpayment of the consumer workforce. For example, Yates et al (2011) compared eight consumer-operated service programs in terms of cost-effectiveness and concluded that programs should be designed so they can rapidly increase or decrease staff and facilities in response to consumer demand, "minimising fixed costs," including using ad hoc rented spaces in preference to longer-term leases, and using volunteer labour and not paying staff higher salaries. By contrast, Holter et al (2004) specifically point to consistent funding and adequate building spaces as two of the top issues for effective consumer-run services. Treating services provided by consumers as simply a cheap source of labour is likely to undermine working conditions for consumers (and may also cause understandable resentment from other professionals, as reported by Nestor et al (2008)).

Sub-question (b): What are the enablers and barriers associated with 'optimal effectiveness'?

> "Pressure to implement consumer-providers without thoughtful planning may result in tokenism, setting up the consumer, providers, and the agency for unforeseen barriers and challenges." (Garrison 2010:2)

Some key challenges in implementing consumer work more generally have been consistently identified in the literature and some thoughtful, experientially-based strategies to address these challenges have also been articulated (Carlson et al 2001, Stewart et al 2006, Biedrzycki 2008, Orwin 2008, Maclean 2009, Garrison 2010, Davidson et al 2012, Bennetts et al 2013, Byrne 2014, Ahmed 2015). These challenges can be divided into three categories:

- organisational commitment to consumer work;
- attitudes and practices of non-consumer colleagues;
- supports and conditions for consumer workers.

Insufficient research has been conducted into consumer-operated services to identify barriers and enablers specific to this context. Some of these barriers identified in the more general peer-delivered service literature might be assumed not to be relevant consumers employed in consumer-operated services, but the literature suggests otherwise (e.g. CMHA 2005, Hardiman et al 2005, Alberta et al 2012, Moran et al 2013, Ahmed et al 2015). CMHA (2005) found that peer workers were often paid less in peer-run organisations than peer workers in other organisations, due to lack of funding. Ahmed et al (2015) found peer specialists in a statewide consumer network faced poor compensation, limited employment opportunities, work stress, emotional stress and challenges in maintaining personal wellness. Hardiman et al (2005) report that other professionals tend to devalue services offered by consumer workers, and that this impacts on consumers working in consumer-run services when they interface with other services. Likewise, Alberta et al (2012) reported on a number of peer-run centres auspiced by a larger community mental health organisation and noted that the peer workers were relegated to a 'sort of junior status' and there was a reluctance among non-peer staff to cede real control over the service delivery process; they conclude that 'Although the centers operate as freestanding entities, these challenges still confront PSS [peer support staff], as they regularly come into contact with professional staff members associated with other organizations.' Moran et al (2013) examined experiences of peer workers in both traditional and peer-run services and found that workers in both found the conditions poor (including low pay, stress and burnout), lack of role clarity and insufficient training. Workers in peer-run organisations additionally experienced a lack of role clarity and loose work structure and roles.

Organisational commitment to consumer work

An issue that can either be an enabler or barrier to effective consumer work is organisational commitment (or lack thereof) to the value (and values) of consumer work: organisational recognition that consumer

workers offer something that is of particular value (Biedrzycki 2008). This involves clear identification and valuing of the unique contribution made by consumer workers, rather than, for example, peers 'being assigned tasks that other staff are simply too busy to perform (such as filing or providing transportation)' (Davidson et al 2012). While this is especially true of non-consumer organisations that employ peer workers, it is also relevant to funding bodies, policy makers and organisations that auspice stand-alone consumer-operated services. Organisational commitment includes strong and consistent championing, active support and commitment to understanding consumer work from senior managers, funders and policy makers, addressing systemic issues, prioritising the development of consumer work and setting an example for other staff and organisations (Biedrzycki 2008, Orwin 2008, Maclean 2009, Davidson et al 2012). Furthermore, this commitment extends into thinking longer-term: as Garrison (2010) notes, 'Commitment by an agency to create positions specifically for consumers as providers should also involve a longer-term commitment to assist these individuals in developing a long-term professional career.'

Attitudes and practices of non-consumer colleagues

Another factor that has tended to be a barrier, but can be an enabler, is the attitudes of non-consumer colleagues. Some peer workers have felt that they have to prove themselves to their colleagues (Bierdzrycki 2008). Nestor et al (2008) point to non-consumer staff fears that they will be replaced by peer workers, especially if they are seen as a cheaper alternative, and fears of being observed and negatively evaluated by peer workers. Mancini and Lawson (2009) describe consumer workers as performing significant emotional labor in negotiating their working relationships, and as requiring relevant supports to avoid emotional exhaustion and burnout. Consumers working in consumer-operated services no doubt are shielded from having to negotiate these attitudinal barriers on a daily basis but, as noted above, these issues are relevant at the interface between consumer-operated services and other services.

Consumer work is most effective when it is actively supported by non-consumer colleagues: the Consumer Involvement Station (2014) describes this in terms of "allies" - non-consumers who actively champion and support consumer workers. Specific training may be needed to prepare organisations who engage with consumer workers (Biedrzycki 2008; Garrison 2010), including consumer-operated services, including training in peer philosophies, expectations of peer staff, disability and discrimination legislation and its implications for hiring and the provision of reasonable accommodations (for example, Davidson et al (2012) note that some measures used to ensure that consumer workers are "well enough" to work, such as mandatory Wellness Recovery Action Plans, may constitute discrimination under disability law). It has been noted that non-consumer colleagues tend to become more positively disposed towards consumer workers when they have contact with them, are able to ask questions and see the results of their work (Maclean 2009).

Hodges and Hardiman (2006) discuss in detail issues arising from partnerships between consumer-run and more traditional services, advocating strongly that such partnership are desirable. More work needs to be done in the Australian context to examine the strengths and challenges of different organizational structures. It is highly likely that, in practice, specific local conditions will influence – if not determine – what kinds of structures are most desirable and feasible.

Supports and conditions for consumer workers

There is wide-spread concern in the literature about the sub-optimal working conditions for consumer workers, leading to what Byrne (2014) in a PhD-length study of the lived-experience workforce describes as "risk to self" for those engaged in lived-experience work. It is important to clarify that this does not mean "risk of relapse" (based on an assumption that consumer workers are inherently vulnerable, due to their consumer status), but rather is an observation about the ways in which consumer workers are put under

unnecessary stress by inadequate working conditions. If reasonable accommodations are needed, these need to be understood in the context of disability law, rather than therapeutic supports.

Role clarity has been identified as important, including a clear job description (Carlson et al 2001, Davidson et al 2012, Bennetts et al 2013, Walker 2013); although Bierdrzycki (2008) notes that this may involve a period of learning and progressive role-clarification in contexts where consumer workers are new to an organisation. Career-development is another issue that needs to be addressed (Bennetts et al 2013, Health Workforce 2014).

Training is another issue that has attracted attention in the literature. Walker (2013) and Alberta et al (2012) observe that the wrong kinds of training can potentially lead to the "professionalisation" of the consumer workforce, that is, consumers being pushed to take on the values and practices of other disciplines, interfering with the advantages of consumer work. Training needs to be faithful to the philosophical underpinnings of consumer work (rather than, for example, generic training in Strengths-based approaches, suicide prevention and aggression management), including specific skills in how to use lived experience in the workplace (Davidson et al 2012). There is no consensus in the literature about whether such training should be in-house, or of any particular model, although it is argued that training needs to be offered by other consumers, rather than by educators with no experience in peer work (Orwin 2008). Training needs to be understood as ongoing, and as capacity building (Bierdrycki 2008).

Supervision has been identified as a critical issue (Orwin 2008 suggests supervision is "the most critical aspect" in successful peer support). There are differences of opinion within the literature about what constitutes best practices in supervision for consumer workers, although most suggest a range of options so consumer workers have choice, including supervision from other consumers or from non-consumers (particularly when this is contextualised in terms of consumers being treated the same as all members of the team), internal and external supervision (although Orwin 2008 suggests supervision needs to be external to the consumer workers' team), individual and group (Bierdrzycki 2008). Supervisors need to understand consumer work, its philosophical underpinnings and be trained as a supervisor (Orwin 2008). Part of the role of a supervisor to consumer workers is supporting them to "stay peer," which may be more difficult for non-consumer supervisors. Mentoring has also been mentioned as a potential support for consumer work (Biedrzycki 2008). Mutual support contexts also have value, such as monthly gatherings for consumer workers to network, discuss issues of concern and share experiences with each other (Carlson et al 2001).

A final enabler that may be of relevance to the NSW context is discussed in Rogers (2010) - Technical Assistance Centres designed specifically to support consumer-run services, including supporting recovery-orientation and consumer empowerment in the planning, delivery and evaluation of mental health services. Our Consumer Place in Victoria (www.ourconsumerplace.com.au) was initially established with this vision in mind. While there has been no formal evaluation of the impact of TACs (and it's likely that their impact is too diffuse to be measured directly), it makes sense that a centralised resource centre could be of benefit, both to consumer-run services and to non-consumer-run services that might want support with employing consumer workers and increasing their recovery orientation.

Sub-question (c): Is there evidence for differences in effectiveness outcomes across population sub-groups of interest to the agency?

There is very little evidence for effectiveness of outcomes for consumer-operated services (of any kind) across population sub-groups of interest to the MHC:

- Rural and remote;
- Culturally and linguistically diverse (CALD);

- Aboriginal people;
- Lesbian, gay, bisexual, and transgender (LGBT).

A broader scope of literature has been included that may offer insights relevant to these groups. Two studies looking at peer support interventions explicitly included rural participants (Griffiths et al 2010, Cook et al 2011): Griffiths et al (2010) did not include the results of their study but did note the likely usefulness of online communities for rural consumers, while Cook et al (2011) noted that the positive results of a 12-week, peer-supported, manualised program on various recovery measures (hopefulness, empowerment, self-esteem, self-assertiveness) were comparable across urban, suburban and rural participants.

Te Pou (2010) point to the importance of actively recruiting consumer workers from ethnic minorities so that the workforce more closely reflects the service-user population. This extends to those supervising consumer workers (Tondoro 2010). Tondoro (2010) specifically sought to engage Latinos and African Americans in peer support groups, including questions about participants' cultural needs and culturally relevant experiences, including running groups in Spanish where appropriate. Their experience was that Latino participants were "difficult to engage" in social activities, since they stated they already had well-developed community and social networks. Orwin (2008) examined the role of peer support for Maori, Pacific Islander and Chinese participants, describing how peer support has been adapted in specific cultural ways, for example by involving the broader (ethnic) community in training and support, and by recognising a more collectivist sense of wellbeing (rather than focusing on individual autonomy). A number of roles that peer support workers play in these ethnic communities are described, including acting as surrogate family for consumers who are culturally dislocated, or as a cultural translator of the mental health system. Faulkner et al (2014) note that members of some minority communities find support in community-based organisations, rather than mental health-specific organisations. Faulkner and Kalathil (2012) interviewed participants in various mental health peer support environments and found that ethnic-specific mental health groups were particularly valued by members, who found communal solidarity and a strengthening of identity beyond mental health. Tondoro (2010) by contrast, found that some participants experienced such groups as "discriminatory." Goldstrom et al (2006) observed that for some ethnic minority groups in the US, groups run by spiritual or religious leaders may be described by participants as 'self-help groups' but would most likely fall outside of most definitions of consumer-operated services. Sav et al (2014) differentiate between consumer health organisations (CHOs) that are "condition based" (e.g. the National Schizophrenia Fellowship) and those that are "population based", where the focus is on a wider spectrum of issues faced by a particular community (e.g. Muslim Youth helpline). Their study involved in-depth, qualitative interviews with nearly 100 people with chronic health conditions (including, but not limited to mental health issues) and their carers and included an unusually large proportion of participants who were Aboriginal and Torres Strait Islander (24%) or from Culturally and Linguistically Diverse backgrounds (22%). They found that CHOs were experienced as valuable resources, providing information, connection and support for learning about self-management, but did not differentiate in their discussion between "condition" and "population" based organisations.

Rogers (2013) examined 69 LGBT services in the US (ie. services that were not mental health-specific) and evaluated their mental health supports, finding that many mental health needs were met by these services. Rogers (2013) also noted that LGBT services tended to be concentrated in urban areas and that the better funded organisations were better able to cater to the diversity of the LGBT community (e.g. providing services specifically for youth and people of color).

While there is limited evidence to make any conclusions on the basis of this literature, this is clearly an area that warrants for further investigation. Of course, consideration of these issues should integrally involve members of these communities.

Sub-question (d): What are the features of 'successful' consumer run and/or led services? For the NSW setting, are there any key recommendations for best practice in mental health services and the place for consumer led/run components (i.e. including issues of governance or business model)? The reviewer is welcome to suggest an innovation or framework as a case study.

It is clear from the research conducted by Clay et al (2005) (see also Campbell 2006 and Rogers 2007), as well as the surveys of Ostrow and colleagues (Ostrow et al 2014) and Goldstrom et al (2006) that a wide variety of consumer-operated services – of different sizes and structures and focused on different activities – can be successful.

The Consumer-Operated Services (COS) Program in Queensland offers a promising model for adoption in other states. These services adopt an Intentional Peer Support approach, and are the most elaborated model of consumer-run services in Australia. The evaluation of these services (Australian Healthcare Associates, 2013) demonstrates a high level of satisfaction of service users with these services, including detailed description of *how* participation has impacted upon participants (especially highlighting how participation in COS has led to reduced hospitalisations) but also the difficulty of imposing standardised evaluation criteria on a service that has a fundamentally different philosophical approach. For example, it was difficult to establish concrete participation rates, due to the explicitly fluid nature of people's involvement with the service - people were always free to come and go, using the service as they saw fit and "attendance records" were not kept. A second example was the rejection of the Recovery Assessment Scale (RAS), a commonly used tool for measuring recovery, because RAS was described as over-emphasising goal-setting, whereas Intentional Peer Support offers a more nuanced approach to how change occurs in people's lives. Measures like the RAS are well-suited to research that demands concrete, measurable outcomes, but may not capture the nuances of what occurs in consumer-run service contexts.

Another model that shows promise is the emergence of peer-run respites as alternatives to hospitalisation (e.g. Vestal 2015, Australian Healthcare Associates 2013, Croft and İsvan 2013, Bologna et al 2011, Dumont et al 2002). There is a growing body of evidence that such services are a useful addition to consumer options at times of crisis. As well as demonstrating effective outcomes, especially for people for whom hospitalization has not been a positive experience in the past, such programs have also demonstrated significant cost-savings: given the high cost of hospital admissions, this is a particularly attractive option in terms of long-term savings. Like the COS programs in Queensland, many of these use Intentional Peer Support as a training model, although this is not the only model for peer-run crisis respites.

Finally, within the various types of services that are run by consumers, a distinction has been made by a small group of researchers (Segal et al 2002, 2010, 2011, 2013a, 2013b) between what they describe as "organizationally empowering" Self-Help Agencies (SHA) and "hierarchically organised board-and-staff-run Consumer-Operated-Service-Programs" (BSR-COSP). Their research demonstrates that the former service-type promotes more recovery-oriented outcomes, such as increased hope, self-efficacy and empowerment and reduced self-stigma, when compared with either the latter type (hierarchical BSR-COSP) or conventional community mental health services. They argue that "organizationally empowering" Self-Help Agencies "reflect the goals and aspirations of the early leaders of the self-help movement who founded them" and are characterised by several qualities:

> First, the people who use the services also run them and make all decisions—the service providers and recipients are one and the same. Second, these groups strive to share power, responsibility, and skills and endorse a nonhierarchical structure in which people reach across to each other rather than up and down a hierarchy. Third, client-run programs are based on choice: they are totally voluntary. Finally, the programs are based on a nonmedical approach to treating disturbing behavior, and they address the economic, social, and cultural needs of clients." (Segal and Silverman 2002:304)

While the findings of these studies seem compelling, there are many shortcomings in their research methodology. Most critically, only one "hierarchically" organised service was included in any of the research, which means that the findings that this particular service was less effective than the four SHAs (or even than conventional community mental health services) may be due to factors other than hierarchical organisational structure (for example, the service may simply be of poor quality). Moreover, some of the measures used for "empowerment" involve circular logic - the degree to which consumers were actively involved in decisions in the agencies ("organisationally mediated empowerment") was measured and then interpreted to demonstrate that consumers were more empowered because they were actively involved in decisions in the agency. This measure – organizationally mediated empowerment – refers to the degree to which consumers are actively involved in decisions in the organization (e.g. voting for the board, making decisions about operations). Despite its name incorporating the word "empowerment," it is not clear whether this is actually important to people engaging in the organization. While Segal et al's research assumes that higher ratings of "organizationally mediated empowerment" are desirable, Brown et al (2008) found suggest that *social* participation may be more important for recovery-outcomes than *organisational* participation. More (robust) research is warranted to investigate the structural characteristics of consumer-run services that contribute most effectively to recovery-oriented outcomes.

4 Conclusions / policy and practice implications

- A survey be conducted (similar to Goldstom et al 2006 and Ostrow et al 2014 in the US) of existing consumer-operated services in Australia, including their business and governance models and relationships with non-consumer organisations (e.g. are they stand-alone, auspiced or operating in partnership?)

- Greater investment in consumer-operated services be considered, with consumers centrally involved in conceptualising, designing, operationalising and evaluating these services.

- Further research be conducted that explores the qualities of services that are effective, including fidelity to consumer philosophical values. This research may draw more on grey literature and would integrally involve consumer researchers.

- Issues to do with workplace conditions for consumer workers be considered a high priority, including role clarity, career paths, relevant training and supervision, as well as active support and championing from senior management of any auspicing bodies, funders and policy makers, and training for any non-consumer colleagues.

- Consumer-operated services that have overcome any of the barriers identified in this report (e.g. robust training materials, productive and mutually respectful relationships with non-consumer-controlled organisations, clear job descriptions, appropriate pay scales, supervision structures, etc) be encouraged – and resourced where appropriate – to document and share their materials and experiences.

- Evaluation be embedded into any services provided by consumers, to build up the evidence base for what works, in what contexts, and why. Existing consumer-operated services should be encouraged to document those outcomes and indicators that demonstrate program effectiveness, to build up an understanding of what "effectiveness" might look like in practice. Research should be considered that faithfully reflects the philosophical values of consumer work. This does not necessarily preclude quantitative research modalities, but it should mean involving consumers (including consumers from particular sub-groups, where relevant) in the conceptualization, design and implementation of research studies to ensure that research measures are meaningful to consumers. Resources are likely to be needed for this purpose.

- Expertise be sought from consumers with an understanding of the specific needs of subgroups of interest to the Commission to examine the complex issues - alluded to in this report – relating to the relevance of consumer-operated services to these subgroups. This may lead to clarity about any need for further research relevant to these subgroups.

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6 Appendix A: How has the review been conducted?

A pluralistic approach was taken to answering the questions posed in this review, endeavouring to take into account both the peer-reviewed published literature and other relevant literature.

Peer-reviewed publications and reports in academic databases (Cochrane, Medline, PsycINFO and Scopus) were searched, using the search terms "consumer operated services," "consumer run", "consumer led", "peer support" and "mental health." This yielded several thousand results. Articles were excluded that were published before 2000. The resulting literature was then screened for articles in which mental health consumers were providing direct support (to other mental health consumers aged 18-65), and - crucially - which had an evaluative component that measured the effectiveness of this support. This process involved reviewing abstracts and filtering out those not directly relevant to this review. Relevant items from the reference lists of relevant articles were also included. It is possible that some studies have been missed, if their name does not indicate either that they are focused on consumer-operated services, or that they include an evaluative component.

This peer-reviewed literature base was supplemented with grey literature, from the collections of both the reviewers and by conducting a Google search using the same key terms. Materials were included that had national or international significance, and were published after 2005. Given the tight time frame for this review, only a small selection of grey literature was included, focusing primarily on literature that had relevance to the evaluative component of this review.

7 Appendix B: Papers included in the review

Lead author, date	Title	Type of peer involvement	Country	Recovery outcomes (or other outcomes) measured	Consumer involvement?*	Notes on study
Strong evidence: *Studies were considered strong evidence if they included multiple studies that each had robust research design, plus some understanding was demonstrated of the specific value of peer work.*						
Doughty et al 2011	Can consumer-led mental health services be equally effective? An integrative review of CLMH services in high-income countries	Consumer-run services	International	Employment, housing, reduction in hospitalisation (and thus cost of services)	No	29 matched studies compared consumer-led services with traditional services. Overall, consumer-led services reported equally positive outcomes, especially for practical outcomes. Underfunding is mentioned as a barrier. Notes that recovery oriented outcomes should be prioritised in future studies
Solomon et al 2001	The state of knowledge of the effectiveness of consumer provided services	Various consumer-operated services	USA	Various	No	Provides an overview and analysis of the evidence of effectiveness of consumer-provided services, as of 2001. Concludes that there is (at that point) insufficient evidence of the effectiveness of consumer provided services, based on a lack of strength of the evidence. Predicts [accurately] that research is likely to continue to be predominantly examining consumer services as adjuncts to mainstream services, rather than examining stand-alone consumer run services
Moderate evidence: *Studies were considered moderate evidence if they included only a single, robustly designed study or if they included multiple studies but demonstrated a lack of understanding of the specific value of peer work.*						

Lead author, date	Title	Type of peer involvement	Country	Recovery outcomes (or other outcomes) measured	Consumer involvement?*	Notes on study
Cook et al 2012	A randomised controlled trial of effects of wellness recovery action planning on depression, anxiety and recovery	Peer-led manualised intervention (WRAP)	USA	Depression and anxiety symptoms, self-perceived recovery (empowerment, quality of life, hope, meaning of life, and tolerable symptom levels)	Yes	RCT, 519 participants assigned either to a Wellness Recovery Action Plan group (8 weeks of 2.5 hour sessions facilitated by peers in recovery) or to treatment as usual (a waitlist). Interviewed at baseline, after 2 months and after 8 months. WRAP group participants reported significantly greater reductions in symptoms and total Recovery Assessment Scale scores, as well as the subscales measuring personal confidence and goal orientation. It was also found that more WRAP sessions attended correlated with greater improvement
Gestell-Timmermans et al 2012	Effects of a Peer-Run Course on Recovery From Serious Mental Illness: A Randomized Controlled Trial	Peer support	Netherlands	Empowerment, hope, self-efficacy, quality of life, loneliness	No	RCT, 333 participants assigned to either manualised, 12-week peer-run course ("Recovery is up to you") or a wait-list for the course. The peer-run intervention had a significant positive effect on empowerment, hope and self-efficacy, but not on quality of life and loneliness. Effects persisted 3-months after course completion
Cook et al 2011	Randomized controlled trial of peer-led recovery education using Building Recovery of Individual Dreams and Goals through Education and Support (BRIDGES)	Peer educators facilitating a manualised self-management course	USA	Recovery (Recovery Assessment Scale), hopefulness, empowerment, self-esteem, self-assertiveness	Yes	428 participants were assigned either to an 8-week peer-led mental illness intervention or to a wait-list control group. Compared with controls, the participants in the peer-led training had significantly greater improvements in total Recovery Assessment Scale scores, as well as subclass measuring personal confidence and tolerable symptoms, and significantly greater improvement in hopefulness. ***Found comparable results across urban, suburban and rural settings***

Lead author, date	Title	Type of peer involvement	Country	Recovery outcomes (or other outcomes) measured	Consumer involvement?*	Notes on study
Segal et al 2011	Outcomes from Consumer-Operated and Community Mental Health Services: A Randomized Control Trial	Consumer-run services	USA	Symptom severity, personal empowerment, self-efficacy, independent social integration, hopelessness	No	RCT examined the effectiveness of a 'hierarchically organised board-and-staff-run Consumer-Operated-Service-Program (COSP)' - a drop in centre collocated with a Community Mental Health Agency (CMHA). 139 new clients were assigned to either both or just the CMHA and then assessed at both baseline and after 8 months on a measure of symptom severity and four recovery-focused measures: personal empowerment, self-efficacy, independent social integration and hopelessness. Results favoured CMHA-only service, on social integration, personal empowerment and self-efficacy. Neither symptomatology nor hopelessness differed by service across time. **Limitations: findings based on only one COSP**
Segal et al 2010	Self-help and community mental health agency outcomes: A recovery-focused randomized controlled trial	Consumer-run self-help agency	USA	Personal empowerment, self-efficacy, social integration, hope, psychological functioning	No	RCT, 505 participants seeking support at a community mental health agency were randomly assigned to either the agency alone, or to both the agency and one of five consumer-run self-help agencies, managed as participatory democracies. Member-clients were assessed at baseline and at one, three, and eight months on five recovery-focused outcome measures. Overall results showed significant differences in favour of the combined services

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Tondora et al 2010	A clinical trial of peer-based culturally responsive person-centered care for psychosis for African Americans and Latinos	Consumers offering support to participate in treatment planning and facilitating social activities	USA	Self-management, satisfaction with services, quality of life	Yes	RCT, involving Latinos and African Americans (on the basis that ethnic minorities tend to be most disenfranchised in the mental health system), with psychotic diagnoses. 120 people in each of three groups: control group received standard care (Illness Recovery Management), 2 experimental groups were also offered peer mentors who facilitated more active participation in treatment planning meetings, while one group also had peer-run weekly social/recreational activities. Participants were explicitly asked about their cultural needs and culturally relevant experiences. Assessed at baseline, 6 months and 12 months post-intervention. Both interventions and research conducted in English or Spanish where appropriate. RCT results not published yet. The fact that the supervisory staff were all Caucasian caused significant tension. One participant found the groups' ethnic segregation uncomfortable and discriminatory. Also found that 6 months was too short to build trusting relationship with peer supporter. Research concern was also expressed that some of the peer workers were available to the participants in peer centre roles. 'Skilled and assertive" peer staff were required to attend additional "art of diplomacy" training in response to their advocacy efforts. "This training was necessary in order to foster a productive team dynamic where the mentor would be perceived as a helpful supplement rather than as an external threat or critic." (2010:376). A challenge to the study was a conflict between the desires of participants (to engage with one, trusted peer) and the research design. It was also found that Latinos were "more difficult to engage" in the social side, as they stated they already had well-developed community and social networks

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Greenfield et al 2008	A randomized trial of a mental health consumer-managed alternative to civil commitment for acute psychiatric crisis	Consumer-run crisis alternative	USA	Costs, level of functioning, psychiatric symptoms, strengths, treatment satisfaction	No	RCT, 393 participants. Compared two groups - consumer-run crisis residential program, emphasising client decision and involvement in recovery, or locked, inpatient psychiatric facility run by medically trained professional staff. Participants in the consumer-run crisis residential program had significantly greater improvements, including fewer psychiatric symptoms and greater life satisfaction
Rogers et al 2007; see also Campbell 2006 and Clay et al 2005	Effects of participation in consumer-operated service programs on both personal and organizationally mediated empowerment: Results of multisite study	Various consumer-operated service	USA	Empowerment, social inclusion, well-being, housing, employment, hope, recovery, program satisfaction	Yes	RCT involving 8 sites, 1827 participants. Recruited from traditional mental health services and randomised to either add consumer-operated service (COSP) or not. Diverse COSP models including drop-in centres, mutual support groups and educational/advocacy programs. Individuals participating in the COSPs perceived higher levels of empowerment than those in the control group and greater attendance at the COSPs increased this effect. Overall effect sizes were modest, due to large variations between the effectiveness of different COSPs. Specific attention was paid to the cultural appropriateness of outcome measures (review by a panel with cross-cultural expertise); some sites also specifically sought to create a representative ethnic mix of participants, although nothing was reported of any impact of these measures on the results. Participation in the COSPs was entirely voluntary: some people who were assigned to the COSP experimental condition did not all participate in the COSPs and were in no way pushed to be involved (ie participation was entirely voluntary)

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Rowe et al 2007	A peer-support, group intervention to reduce substance use and criminality among persons with severe mental illness	Peer support	USA	Alcohol use, drug use, criminal justice charges	Yes	Experimental group used community-oriented group intervention with citizenship training and peer support, combined with standard clinical treatment, including jail diversion. Control group used just standard clinical treatment with jail diversion. Experimental group showed significantly reduced alcohol consumption compared with control group. Drug use and criminal justice charges decreased significantly across both groups
Nelson et al, 2006a, b, 2007, Ochocka et al, 2006; Janzen et al 2006	A longitudinal study of mental health consumer/survivor initiatives: Part 1–Literature review and overview of the study; Part 2–a quantitative study of impacts of participation on new members; Part 3–a qualitative study of impacts of participation on new members; A longitudinal study of mental health consumer/survivor initiatives: Part 4–Benefits beyond the self?; Part 5–Outcomes at 3-year follow-up	Peer support	Canada	Quality of life, hospitalisation, use of emergency services, employment and education	No	118 participants, four entirely consumer-run organisations v no service. Qualitative and Participatory Action Research. Participants in consumer-run orgs had small increase in quality of life, fewer days spent in psychiatric hospital, less use of emergency services, greater participation in employment or education; more stable mental health, enhanced social support, sustained work, stable income. These results continued after 3 years
Burti et al 2005	Does additional care provided by a consumer self-help group improve psychiatric outcome? A study in an Italian community-based psychiatric service	Self-help group	Italy	Hospital admissions, duration of stay in hospital, higher levels of service satisfaction, symptoms	No	2-year study, 88 participants. Consumer run self-help group v regular community mental health services. Clients who attended consumer-run self-help group decreased their number of admissions during the study period and duration of stay in hospital; and had higher level of service satisfaction. Non-self-help group members identified higher number of unmet needs. No difference in symptoms

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Dumont et al 2002	Findings from a consumer/survivor defined alternative to psychiatric hospitalization	Consumer-run crisis alternative	USA	Empowerment, shorter hospital stays, fewer hospital admissions	No	RCT, 265 participants, assigned either to a consumer-run crisis hostel and peer support or access to hospital-based services only. Those with access to the hostel had significantly fewer hospital admissions, shorter duration of stays in hospitals and greater levels of satisfaction with services. Cost per patient for crisis services was reduced by almost a third
Chinman et al 2001	Chronicity reconsidered: Improving person-environment fit through a consumer-run service	Consumer-run program	USA	Hospital admissions	Yes	158 participants, matched-comparison group, longitudinal study, either outpatient services or outpatient services plus a consumer-run Welcome Basket Program. Clients who received both had 50% reduction in hospitalisations. However, comparison of matched samples suggested no difference in either the number of re-admissions to hospital or the number of inpatient days

Weak evidence: Studies were considered weak if they included only a single study, and this study had significant limitations, or if they demonstrated a considerable misunderstanding of consumer work.

Australian Healthcare Associates 2013	Evaluation of the Community Mental Health Intentional Peer Support Training and Consumer Operated Services	Consumer operated services	Australia	Ability to manage daily life, better relationships, improved ability to manage emotions, improved social interaction and reductions in hospitalisations	No	Questionaires were filled out by 36 participants in Consumer Operated Services (COS), reflecting on how the service users had benefited from participating. More standardised measures were rejected as misaligned with the programs' philosophical underpinnings. Participants were very satisfied with the COS programs and with Intentional Peer Support model and a number of recovery benefits were found. Some changes were suggested to the structure of the training, including an accreditation process

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Corrigan 2013	The impact of self-stigma and mutual help programs on the quality of life of people with serious mental illnesses	Mutual help groups	USA	Quality of life, self-stigma	Yes	85 people who had used mutual help groups - specifically noted as an example of a Consumer Operated Service - completed self-reported measures of quality of life, self-stigma, group identification and social support. They found that *satisfaction* rather than just *participation* in mutual help programs was associated with reduced self-stigma, increased group identification, social support and quality of life
Croft et al 2013	Impact of the 2nd Story Peer Respite Program on Use of Inpatient and Emergency Services	Peer-run respite	USA	Use of emergency and inpatient services	Yes	Matched pairs of 139 users of a peer respite and 139 non-users with similar histories of behavioural health service use and demographic characteristics were compared. The odds of using any impatient or emergency services after the program start were approximately 70% lower among respite users than among non-respite users, although the odds increased with each additional respite day. Among individuals who used any impatient or emergency serices, a longer stay in respite was associated with few hours of impatient and emergency service use. However, the association was one of diminishing returns, with negligible decreases predicted beyond 14 respite days
Jones et al 2013	Peer Support, Self-Determination, and Treatment Engagement: A Qualitative Investigation	Peer-led WRAP groups	USA	Self-determination and self-awareness, advocacy, medication-related decision-making and meaningful engagement with traditional providers	Yes	Focus groups with 54 participants/facilitators of Wellness Recovery Action Plan (WRAP) groups, analysed using grounded theory. Found general consensus about the value of the group on a variety of measures of recovery, and a diversity of participant experiences with medication. Study specifically challenges "treatment adherence" as a goal for recovery-oriented services, supporting self-determination instead

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Segal et al 2013a	Are all consumer-operated programs empowering self-help agencies?	Consumer-run services (both consumer-board-run and participatory democracy)	USA	Empowerment	No	Participant democracy-style organisations increased (self-rated) participant empowerment more than consumer-board-staff-run organisations
Segal et al 2013b	Self-stigma and empowerment in combined-CMHS and consumer-run services - Two controlled trials	Consumer-run services (both consumer-board run and self-help)	USA	Self-stigma, organizational empowerment, self-efficacy	No	The study compared the relative effectiveness of two types of consumer-run services (in conjunction with a community mental health agency) and also compared them with a community mental health agency alone. Participants in the participatory democracy self-help agency experienced the most positive changes, while participants in the hierarchical organisation showed negative changes. Limitations of the study include that only one "hierarchical" consumer-run organisation was involved and the study assumes that the operative difference was the style of participation structure (rather than, say, a poorly run service)
Pickett et al 2012	Peer-led Recovery International groups for mental health consumers	Peer-led groups	USA	Psychiatric symptoms	No	79 participants, no control group. Interviewed participants about the benefits of participation in Recovery International. Participants reported increased skills in being able to cope with their illness

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Bologna et al 2011	Evaluation of a Peer-Run Hospital Diversion Program: A Descriptive Study	Peer-Run hospital diversion program	USA	Quality of life (including life satisfaction and social involvement)	Yes	An uncontrolled, single-site evaluation of participants in a peer-run hospital diversion program's perceptions of care and recovery, comparing their experience with a non-peer-run acute inpatient program. A purposive sample of 39 participants rated the quality and type of services they received and their beliefs about the impact of these services on their recovery and life satisfaction. Peer-run service seen as more client-centred, less restrictive and the staff more respectful, decreasing stigma and increasing life satisfaction and social involvement
Fukui et al 2010	Pathways to Recovery (PTR): Impact of Peer-Led Group Participation on Mental Health Recovery Outcomes	Peer-led groups	USA	Self-esteem, self-efficacy, social support, spiritual well-being, and psychiatric symptoms	No	Found positive results for participants in peer-led groups, but very small study with no control group. Also the content of the course was not peer-developed (it was written by social workers)
Barbic et al 2008	A randomized controlled trial of the effectiveness of a modified Recovery Workbook program: preliminary findings	Manualised peer-led group	Canada	Hope, empowerment, Recovery Assessment Scale, quality of life	No	RCT, 33 participants, randomly assigned to either assertive community treatment services, or assertive treatment services plus a Recovery Workbook group (12 week course). Perceived levels of hope, empowerment, recovery and quality of life were assessed at baseline and after 12 weeks. Participation in group led to positive changes in hope, empowerment and recovery but not quality of life
Castelein et al 2008	The effectiveness of peer support groups in psychosis: a randomized controlled trial	Peer support (minimally guided group)	Netherlands	Social network, social support, self-efficacy, self-esteem and quality of life	No	RCT, 106 participants all with psychosis. 8 months peer support vs control group (wait list). Peer support group had a positive impact on social network and social support compared with control condition. High attenders favoured over low attenders on increased social support, self-efficacy and quality of life. Limitation: Groups were "minimally guided" by nurses

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Hodges et al 2008	Predictors of hope among members of mental health self-help agencies	Consumer-run self-help agency	USA	Hope, self-efficacy	Yes	Interviews with 310 long-term users, many (49%) homeless, of four self-help agencies, in which participants actively shaped the service. Study concluded that "SHAs [Self-Help Agencies] are hope-inducing, empowering agencies." Correlation found between agencies that actively involved participants and self-efficacy and hope. Limitations: no control group
Lawn et al 2008	Mental health peer support for hospital avoidance and early discharge: An Australian example of consumer driven and operated service	Peer support	Australia	Bed days saved, crisis service contact, ED presentations, and readmission rates	No	Based on 3 months of operation, 49 packages of support were offered by peer supporters, leading to an estimated saving of 300 bed days (using the participants' prior experiences of hospitalisation as controls), which was calculated as $93,150 saved
Corrigan 2006	Impact of Consumer-Operated Services on Empowerment and Recovery of People with Psychiatric Disabilities	Peer support	USA	Empowerment; confidence and hope, willingness to ask for help, goal orientation, symptoms, self-esteem & self-efficacy + more	Yes	1824 people indicated whether they had participated in peer support programs or not. Small improvements on many recovery measures
Nelson et al 2006	Quantity and quality of participation and outcomes of participation in mental health consumer-run organizations	Consumer-run organisation	Canada	Social support, community integration, quality of life, personal empowerment, employment and education	No	They studied the participation patterns and recovery of 79 new members in 4 consumer-run organizations in Ontario, over 18m months. Positive outcomes were found in a number of recovery domains, particularly at 9 months, and were found to be dependent on service satisfaction (ie. whether they were satisfied with the service and would recommend it to others) but not on the amount of participation

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Segal et al 2002	Determinants of client outcomes in self-help agencies	Consumer-run self-help agency	USA	Independent social functioning, assisted social functioning, personal empowerment	Yes	255 long-term users of four self-help agencies were interviewed at baseline and at 6 months. Personal empowerment increased, independent social functioning remained the same, while assisted social functioning decreased over the period. There was a positive association between 'organisationally mediated empowerment' (ie. how much participants could meaningfully participate in decisions about their care and the way the organisation delivers services) and all three outcomes
Yanos et al 2001	Consumer-run service participation, recovery of social functioning, and the mediating role of psychological factors	Consumer-run services	USA	Social functioning	No	60 participants, drawn from 2 peer-run services and one community mental health service. Found that consumers using peer-run services had better social functioning
Van Tosh et al 2000	Consumer-operated self-help programs: A technical report	Peer-run programs	USA	Independence, empowerment, self-esteem, social support	Yes	Examines 13 peer-run programs, based on self-reporting by participants. The main emphasis of the report was on program descriptions, goals and objectives, with evaluation as a very small element. The resource is dated but still a valuable articulation of what peer-run services are able to do

*A "Yes" for this column was based on either (a) consumer participation in the research process being explicitly acknowledged or (b) study authors who are professionally identified as consumers. There may be some errors, for example where authors who are consumers have not chosen to identify themselves as consumers explicitly for the purposes of the article.