

How do consumer leaders co-create value in mental health organisations?

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Abstract

Objectives. Contemporary mental health policies call for consumers to be involved in decision-making processes within mental health organisations. Some organisations have embraced leadership roles for consumers, but research suggests consumers remain disempowered within mental health services. Drawing on a service-dominant logic, which emphasises the co-creation of value of services, the present study provides an overview of consumer leadership within mental health organisations in the Australian Capital Territory.

Methods. Mental health organisations subscribing to the local peak body mailing list were invited to complete a survey about consumer leadership. Survey data were summarised using descriptive statistics and interpreted through the lens of service-dominant logic.

Results. Ways in which organisations may create opportunities for consumers to co-create value within their mental health services included soliciting feedback, involving consumer leaders in service design, having consumer leaders involved in hiring decisions and employing consumer leaders as staff or on boards. Strategies that organisations used to develop consumer leaders included induction, workshops and training in a variety of organisational processes and skills.

Conclusions. The findings of the present study extend the application of a service-dominant logic framework to consumer leadership within mental health organisations through consideration of the diverse opportunities that organisations can provide for consumer co-creation of service offerings.

What is known about the topic? Policy calls for consumer involvement in all levels of mental health service planning, implementation and delivery. The extent to which service organisations have included consumer leaders varies, but research suggests that this inclusion can be tokenistic or that organisations choose to work with consumers who are less likely to challenge the status quo. Service literature has explored the way consumers can co-create value of their own health care, but is yet to explore consumers' co-creation of value at a systemic level.

What does the paper add? This paper outlines ways in which mental health organisations report involving consumers in leadership positions, including having consumers on boards, having consumers on recruitment panels and providing leadership training for consumers. These initiatives are considered in terms of the potential value co-created within mental health services by consumers in leadership, suggesting that consumer leaders are a resource to mental health organisations in terms of the value brought to service offerings.

What are the implications for practitioners? Research suggests that medical professionals have been resistant to increased consumer leadership within mental health services. The findings of the present study emphasise the value that can be brought to service organisations by consumer leaders, suggesting that mental health practitioners may reconsider their approach and attitudes towards consumer leadership in the sector.

Additional keywords: consumer participation, partnership.

Received 21 April 2016, accepted 30 July 2016, published online 23 September 2016

Introduction

Increased consumer leadership within mental health organisations has arisen from a need to bring about change within mental healthcare.¹ Governments and peak bodies have supported greater consumer leadership in mental health services, with mental health policies in various jurisdictions, including North America, Australia and Europe, demanding increased involvement of consumers within organisations.^{2–4} Research in the field suggests that traditional health service providers are restricting consumer involvement to less important decision making,⁵ selecting consumers believed to be more accepting of the status quo over those consumers more vocal about change⁶ or only allowing consumers to have tokenistic involvement.⁷ Nonetheless, in addition to complying with policy, increasing consumer leadership in mental health services has potential to increase the value of service organisations' offerings.

When referring to systemic participation in decision making, Happell and Roper⁸ suggest that the term 'consumer leadership' more aptly describes meaningful integration in organisations than terms such as 'consumer participation'. Consumer leadership within organisations involves roles such as managing, planning, funding or researching.⁹ Such roles acknowledge that consumer leaders have the power to make important decisions and to manage resources. As consumer leadership roles have developed, discussions within the consumer movement have arisen questioning consistency in the sector with regard to leadership training, the scope of responsibilities and issues of recruitment and pay.¹⁰ These inconsistencies and issues relating to consumer leadership represent some of the barriers to creating meaningful reform.

Traditional mental healthcare structures (like healthcare services more generally) have tended to be hierarchical, characterised by stark power differences between service providers and consumers.¹ Despite the consumer movement gaining some ground, this power difference is still evidenced in the way that the service provider chooses the means and degree to which consumers can participate with its organisation or processes.¹¹ Thus, it is the organisations that have the power of determining the extent of leadership or participation. This view was also put forward by consumer workers in an interview study about workforce issues in mental health services.⁷ In recognition of this power imbalance, organisational practice and research attention has started to explore how consumer leadership may be fostered.

Although the goal of mental health policies is to improve mental health service delivery within government, private and community sectors,⁴ far more research attention has been given to consumer leadership within consumer-run organisations^{12–14} than to the ways in which consumer leadership forms a part of other private or public sector specialist mental health services. The research exploring consumer-run mental health organisations represents important insights in mental health consumer leadership. These insights include the way that consumer leadership can be seen to be a resource in itself for consumer-run mental health organisations,¹⁵ and how organisations may need to work to balance the ideology of consumer leadership with the hierarchies entrenched in traditional health service delivery.^{15–18} A search of the literature for consumer leadership conducted

by the authors revealed that 27 of 36 published articles about consumer leadership were specifically about consumer-run organisations.¹⁹ Thus, whereas there is some extant literature about consumer leaders within consumer-run organisations, there is a gap in current research knowledge of consumer leadership within the mental health sector more broadly.

The present study identifies dimensions of consumer participation in mental health services and proposes ways in which consumer co-creation of value could be developed within these dimensions. Research about value creation in mental health service provision has started to consider the way in which involvement by consumers in health service provision improves organisations' offerings.²⁰ This body of work is rooted in the framework of service-dominant logic, which stipulates that 'relationships, mutual trust, and win-win exchange' between service providers and service consumers lead to these parties co-creating value in the provider-consumer dynamic.²⁰ In the framework of service-dominant logic, the cocreation of value is defined as the work of multiple parties (cocreation) contributing to each other's well being (value), and a foundational premise of the framework is that value co-creation is coordinated through rules, norms and beliefs that determine the actions of each party.²¹

In the health domain, the service-dominant logic framework has provided, for example, useful descriptions of what consumers do at the individual level to co-create value in service delivery (e.g. choosing medical teams for treatment or complying with medications)²² rather than at the organisational or governance level. In terms of mental health services specifically, this body of literature has recently started exploring the how consumers and organisations may improve services through increasing organisational capabilities for consumer involvement (e.g. identifying and engaging consumers who want more active roles in service innovation).¹¹

The service-dominant logic framework has not yet been applied to consumers of health services co-creating service value in terms of leadership of organisations. However, research undertaken from the service-dominant logic perspective has addressed the added value from consumers influencing leadership of health organisations. The traditional method of organisations' interactions with consumers has been through soliciting feedback. Findings from interviews with healthcare executives emphasise the importance of organisations responding to consumer feedback in a timely manner.¹¹ Timely and appropriate response to consumers' feedback is one way to ensure that consumer participation in the process represents co-created value and is not tokenistic. One aim of the present study was to better understand how consumer leadership could add value to mental health service provision.

Understandings of how organisations create opportunities for co-creation of value in mental health services are still developing. Policies direct organisations to operate with consumer involvement at all levels, but the service-dominant logic literature is yet to explore how mental health services achieve this level of co-creation. Another aim of the present study was to apply the service-dominant logic framework to better understand how consumer leadership can contribute to the co-creation of value (well being of the organisation and consumer leaders) within mental health service delivery.

Methods

Design

The present study was a descriptive study using surveys to collect data. The broad research question was, 'What do organisations do to add value to their services through consumer leadership?' As such, the survey included both quantitative measures of services provided and open-ended questions to elicit more in-depth information about consumer leadership within services. For example, participants were asked about some specific measures of consumer leadership within their organisations, such as whether there were dedicated staff or board member roles for consumers. In addition, participants were given the opportunity to provide more information about the kinds of consumer leadership present within their organisation as a response to open-ended questions such as, 'Are there any other ways in which consumers are currently engaged in organisational leadership?' and 'What systems or practices have presented barriers to consumer leadership in your organisations?'

Setting

Data were collected from within the Australian Capital Territory (ACT). The ACT is particularly well resourced compared with other Australian jurisdictions in terms of consumer leadership, in part because of the emphasis that has been placed on consumers in leadership by the peak bodies for consumers²³ and for the mental health community sector.²⁴ The region has reported the highest number of community service contacts for mental health per capita in Australia²⁵ and has a significantly higher proportion of spending on resources for community mental health services than any other Australian state or territory.²⁶ This context provides useful data to begin exploring contemporary consumer leadership within mental health services.

Participants

Participants eligible for inclusion in the present study were spokespeople from organisations providing mental health services to people within the ACT. Email invitations were sent to organisations in the region through the mailing list of the peak body for the community-managed mental health sector within the region. Twenty organisations are publicly listed as members of the peak body. Participants were in senior roles within their organisations, such as founders, chief executive officers or managers. Of these spokespeople, 13 participated in the study. This represents a response rate of 65% of the 20 member organisations. Responding organisations included a government organisation, a private organisation, a public company and 10 non-governmental organisations (NGOs; one of which was a consumer-run organisation).

Procedure

Email invitations were sent to participants to complete an online questionnaire about their organisation and mental health services. Participants were informed that they were able to request paper versions of the questionnaire, but all surveys were completed online.

Ethics

This study was approved by the University of Canberra's Human Research Ethics Committee before it commenced. The first page of the survey included a note to inform participants that they, as individuals, and their organisation would not be identifiable. Participants were asked to provide their consent by continuing to the second page of the survey.

Data analysis

The data from the survey responses were summarised using descriptive statistics (frequencies and percentages).

Results

Overview of organisations represented

Four of the 13 organisations that completed the survey reported providing mental health services only. The remaining nine organisations reported providing mental health services as well as other programs for specific consumer groups. These programs included advocacy, representational services for other mental health service providers and programs for specific groups, such as lesbian, gay, bisexual, transgender, intersex and questioning (LGBTIQ), or individuals with specific conditions, such as perinatal distress.

Participating organisations included programs aimed generally at individuals with any mental distress ($n=9$), programs for individuals with enduring complex needs as a result of mental distress ($n=3$) and programs for individuals with a specific mental health diagnosis ($n=1$). Across the participating organisations, various programs were represented, including community development or mental health promotion, support or self-help groups, education or training, case management, recreational services, employment services, respite services and rehabilitation. Thus, a diverse range of services was included in the sample.

In terms of the funding arrangements of the participating organisations, five organisations reported being confident in securing government funding based on past success at securing most funds necessary. Five organisations reported looking for ways to improve funding applications because of disappointment with previous success rates. Two organisations reported that they wanted frank advice in order to help them improve their ability to secure adequate funding. One organisation reported that their previous funding applications were subject to unfair and biased processes, and that they would be seeking alternative funding arrangements. Thus, two-thirds of the organisations surveyed were unhappy with their funding arrangements or success.

Table 1 provides an overview of the participating organisations, elaborating on the type of organisation, and the opportunities for co-creation within each organisation. The results discuss ways in which organisations may provide space for consumer co-creation to take place, including soliciting consumers' perspectives, increasing consumers' capacity for leadership and having dedicated roles and responsibilities for consumers.

Consumers' voices

Some responses from organisations related not to consumers in leadership roles themselves, but to ways in which consumer

Table 1. Organisations and opportunities for co-creation
NGO, non-governmental organisation

Organisation	Organisation type	Consumer voice ^A	Leadership capacity building ^B	Dedicated leadership roles ^C
1	Government	✗	✗	✗
2	Private	✗	✗	✗
3	Public company	✗	✗	✗
4	NGO (consumer-run)	✗	✗	✗
5	NGO	✗		✗
6	NGO	✗	✗	
7	NGO	✗	✗	✗
8	NGO	✗	✗	✗
9	NGO	✗	✗	✗
10	NGO	✗		✗
11	NGO	✗		
12	NGO	✗		✗
13	NGO	✗		✗

^AConsumer voice: the organisation reports soliciting consumers' perspectives in terms of satisfaction with or complaints about services, or in the planning of services.

^BConsumer leadership capacity: the organisation reports providing ways for consumer leaders to develop their leadership, such as through training programs.

^CDedicated roles for leadership: the organisation has consumers as staff or board members, has consumers involved in the hiring decisions of other staff or has a constitutional commitment to consumer participation in decision making.

perspectives were solicited. Eleven organisations reported routinely conducting consumer satisfaction surveys or other feedback mechanisms, but two organisations reported that no such feedback was undertaken. All organisations reported having clear and accessible complaints procedures in place for those accessing their services, including plain language posters, online anonymous options for complaints and explanations within new client guides. Twelve of the organisations reported that planning of services is conducted with the input of people who use those services (with the remaining organisation unsure).

Developing consumer leadership

The survey responses indicated there was a range of ways in which organisations reported processes and structures in place to facilitate consumer leadership. The strategies that organisations reported using included asking consumers to nominate how they wanted to be involved after the completion of their program and providing an induction for consumers upon taking part in organisational committees. Organisations also reported identifying particular ways to build the capacity of consumer leaders, such as providing links to other consumers and skill development opportunities (e.g. workshops, conferences or professional development courses), as well as a wide range of training programs. Training programs for consumers provided by the organisations covered areas such as governance, meeting facilitation, advocacy, representation, peer education, mentoring and co-facilitating training programs.

Consumers in leadership

An important aim of the survey was to better understand ways that mental health organisations have consumers within leadership roles. Seven of the organisations surveyed reported that new programs for consumer involvement in organisational processes were introduced within the previous 12 months. Eight of the participating organisations reported a specific commitment to consumer involvement within their constitution or other strategic plans.

Another example of consumers taking part in leadership decisions was their involvement in the hiring of the organisation staff. Only five of the organisations surveyed had consumers involved in these hiring decisions, with seven reporting that consumers were not involved in such decisions and one reporting that consumer involvement was not applicable to their hiring processes.

In terms of individual consumers taking active leadership within the organisational structure, 10 of the organisations surveyed had staff or board members identifying as having lived experience of mental illness (only one definitely did not, with the other two unsure). One organisation also specifically stated that if board membership included consumer leaders with lived experience of mental health concerns, this would add significant value to their service offerings.

Responses to the survey also included some organisational perspectives on the challenges of consumer leadership in mental health service delivery at both the individual consumer leader level and the organisation level. At the consumer leader level, participants flagged that recruitment of consumer leaders with the appropriate skills, competencies and understandings could present a challenge. One organisation spokesperson was also concerned that to take leadership positions, consumers would need to commit time and involvement, which may be difficult for some consumers with ongoing mental health concerns. At the organisational level, challenges mentioned were that consumer leadership would present a culture adjustment for staff, that organisational priorities may conflict with consumer interests and that ill-defined roles and expectations would present problems.

Discussion

The findings of the present study suggest that consumer leadership within the organisations surveyed include practices such as providing feedback and taking part in planning of services, as well as providing more high-level decision making through being involved in hiring decisions and being members of staff and boards of mental health services. Although participants reported that they believed some challenges could be associated with consumer leadership (appropriate recruitment, ill-defined roles and cultural change), some organisations' spokespeople described providing consumer leaders with opportunities to develop skills, to ask consumer leaders about the kind of leadership role they wanted and to provide support during induction.

The results suggest that there are three overarching dimensions in which consumer participation is currently taking place: (1) through organisations soliciting and responding to consumers' perspectives about services; (2) through organisational provision of induction, training and professional

development schemes to increase consumers' leadership capacity; and (3) through organisations providing opportunities for consumers to be involved in leadership through dedicated roles and responsibilities (e.g. recruitment to boards and staff, or having consumers be a part of hiring decisions within services). From a service-dominant logic perspective, each of these dimensions could facilitate consumer co-creation of value to services, and organisations might consider how they can create space for co-creation of value across these levels of participation.

First, in the Consumers' Voice dimension, co-creation of value could be facilitated by organisations paying attention to consumers' values (and not imposing organisational values on consumers). To achieve this, feedback should be sought from consumers in a way that allows them to provide their own opinions, and this feedback should be meaningfully used within service planning, implementation and delivery. Second, in the Developing Consumer Leadership dimension, space could be created for co-creation of value by allowing consumers to decide what types of training and development they need. Third, in the Consumer Leadership dimension, organisations can foster better co-creation of value by working towards eliminating tokenistic practices and by partnering with consumer leaders to collaboratively set agendas for organisations.

Tokenistic involvement of consumers should be eliminated throughout all levels of consumer participation. Research has criticised how organisations have engaged with consumer leaders for only allowing tokenistic involvement⁷ and has distinguished between 'consumer leadership' and 'consumer participation'.⁸ The present study discusses mechanisms for both consumer leadership (e.g. having boards comprising consumers) and consumer participation (e.g. having consumers provide feedback to leadership). From a service-dominant logic perspective, consumers may co-create value within several dimensions of participation. It would be beneficial for the consumer movement and organisations to continue to improve on all dimensions of consumer participation. Although asking consumers for feedback on services may be useful, it should not replace meaningful, authentic leadership of consumers within organisations or the continued leadership capacity building for consumers. Further, providing training and development opportunities for consumers is laudable, but it is also important to avoid tokenism at this level of participation. Organisations should consider what the next step will be for consumers who have received such professional development so that their skills are able to be put to use in a meaningful way. Even where there are dedicated roles for consumer leaders within organisations, it should be ensured that consumers are partnering in decision making and that these roles are not a tokenistic nod to the consumer movement and policy directive. The service-dominant logic perspective posits that working towards co-created value in mental health services could improve service proposition, and thus improve the organisation.

The findings of the present study suggest that mental health service providers still have some concerns about consumers in leadership (e.g. skill levels or reservations about ongoing mental health concerns). Previous research has criticised such views, which assume that additional supports will be necessary for consumer leaders and that the skill sets of these leaders will be low.²⁷ Such assumptions are problematic because they may

become entrenched attitudes, creating a further barrier to improved consumer leadership. The service-dominant logic perspective posits that emphasis should be placed on ways in which consumer leaders could co-create value to potentially enhance organisational offerings. Thus, it may be beneficial for organisations and stakeholders to understand the value brought to services by consumer leaders so that attitudinal barriers are broken down.

Previous research applying the service-dominant logic framework to health has broadened understandings about what consumers do at the individual level to co-create value, such as participating in decisions about their own health care.¹¹ The first major contribution of the present study is that it extends the application of the framework of service-dominant logic to activities that consumers may be able to be involved in at the organisational level to co-create value within mental health organisations. The findings of the present study, interpreted through the lens of service-dominant logic, suggest that value co-creation can occur within organisations that are providing leadership opportunities for consumers in organisational activities, including leadership roles on boards and as staff members.

The present study also extends findings about consumer leadership within the mental health sector more broadly. Previous research has provided some important insights about consumer-run organisations.^{12,28} From a co-creation of value perspective, greater consumer leadership within other mental health organisations may represent a significantly different value experience than consumer leadership within consumer-run organisations. Because the participants in the current study came from a range of organisations, encompassing government, community sector, private and consumer-run organisations, the findings reflect the activities that consumer leaders are involved in within the broader mental health context.

The third major contribution of the present study is to suggest some ways in which consumer leadership may be realised within hierarchies of traditional medical models. The balance between the ideology of consumer leadership and the weight of power hierarchies within mental health service delivery has been noted across several observations of organisations, with McLean¹⁷ providing a particularly detailed account of power relationships within mental health services. The present study elaborates on ways consumer leaders can be empowered by their organisations, such as through the provision of training for various organisational skills or through having consumers involved in the hiring decisions of the organisations. Further, the service-dominant logic approach emphasises the importance of the development of human resource strategies to provide employees with the skills needed to interact with consumer leaders in contemporary mental health service organisations. Such strategies may include linking organisational performance to consumer leadership or having executives model positive responses to the co-creation of value that occurs through increased consumer leadership.

The present study has some limitations. First, the sample was relatively small, with just 13 organisations represented. Nonetheless, the aim of the study was to provide rich discussion regarding the kinds of practices that enable co-creation of value between consumer leaders and mental health organisations. The 13 organisations were also quite diverse, representing large private organisations, smaller consumer-run organisations and

government and community organisations. Second, the survey provided a cross-sectional overview of practices within participant organisations. Given that the area of consumer leadership represents a cultural change within such organisations, more nuanced understandings are needed about how service providers deal with such change over time than the present exploratory study can provide.

The present exploratory, descriptive study into consumer leadership in mental health has highlighted opportunities for the development of better understandings of consumer leaders' roles in the co-creation of value in mental health service organisations. Three dimensions of consumer participation have been identified, but more research is needed to explore in more depth what organisations can do within these dimensions to better facilitate consumer co-created value.

Conclusions

The present study applied a service-dominant logic framework to interpret the findings of a survey of consumer leadership within a range of mental health service organisations. The findings suggest that organisations are currently providing varying opportunities for the co-creation of value between consumer leaders and the organisations. The contributions of the study include extending the service-dominant logic framework to consumer leadership and elaborating on ways in which mental health services are working to overcome historical issues of power and traditional hierarchy to incorporate consumer leadership.

Competing interests

None declared.

Acknowledgement

The authors express their thanks to the Mental Health Community Coalition of the ACT for their assistance with contacting mental health service providers across Canberra.

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