Queensland Alliance
FOR MENTAL HEALTH INC.
Peak body for the mental health community sector

Consumer Participation Report:

Queensland NGO Mental Health Sector

August 2014

Queensland Alliance FOR MENTAL HEALTH INC.

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1. Introduction

1.a. Purpose and Method

This report presents a snapshot of what services are doing to support consumer participation, what they would like to do, and some of the resources they have identified that they already have, and some that they still require, to further this end.

In 2011 the Queensland Alliance for Mental Health (QAMH) commissioned a state-wide survey of member organisations, the analysis of which was published in the *Australian Health Review*.[1] That study was a comprehensive review of the state of the community mental health sector in Queensland, with a specific focus on consumer participation in the production or delivery of the community mental health services they receive.

In June 2014, the lead author of that report, a lived experience academic, was engaged by QAMH to conduct a focus group interview with a sample of those services. The focus group sought to identify three key indicators of consumer participation to monitor and strengthen in the community mental health sector. The focus group provided a deeper insight into their position which informed the development of the survey questions on these three key indicators.

- Consumer feedback for service improvement;
- Consumer roles in formal organisational decision making ; and
- Commitment to supporting a peer workforce.

The focus group was followed up in July by a telephone survey of managers in community-based organisations that provide mental health services in Queensland (n=52). Interpretation of the quantitative data obtained from the service provider survey was described statistically.

[1] Byrne, L., Wilson, M., Burke, KJ., Gaskin,CJ, Happell, B. (2014) Mental health service delivery: a profile of mental health non-government organisations in south-east Queensland, Australia. *Australian Health Review*, 38, 202–207

1.b. Rationale why is consumer participation important

Devoting energy and resources to the goal of meaningful consumer participation needs to be based on evidence and identifiable outcomes. Decades of empirical organizational research have shown that the relationship between service quality and consumer satisfaction depend on the degree of consumer participation[2].

The demand of mental health service consumers to have their voice heard in the formulation of service policy and service provision is long-established. Participation results in improved health outcomes for consumers.[3]

The challenge remains, as the results of this survey demonstrate, that services need support, guidance and performance indicators to structure meaningful routes for consumers to drive their own recovery and participate in the construction of the services and supports to help them do that.

This report has distilled three performance indicators from research and consultation with the focus group that might have the greatest utility for service providers to begin or to expand involvement of consumers.

1) Formal service satisfaction feedback from consumers is the touchstone for other developments. Relevant and reliable ways to collect ideas and experiences of consumers is the organizational equivalent of the therapeutic process of listening. It is at the core of good service provision.

2) After hearing the consumers' voice, it is vital that this leads to codesign of services with genuine decision making roles available. Developing formal decision making roles at all levels embeds consumers values in the organization.

3). As more consumers and carers are being employed both in Australia and internationally, the evidence supporting the involvement of consumers and carers with experience of recovery in supporting their peers is becoming stronger.[4]

This report captures the strengths of the sector in supporting the goals of consumer participation and also the challenges to the development of these strengths, as articulated by the service providers themselves.

[2] Uzkurt, C (2010). Customer participation in the service process: a model and research propositions. *International Journal of Services and Operations Management*, 6(1)

[3] National Consumer and Carer Forum (2010) consumer and Carer Participation Advocacy Brief.

[4] Repper, J. & Carter, T. (2011). A review of the literature on peer support in mental health services. *Journal of Mental Health*, 20(4) 392-411.

2. FINDINGS

2.a. Sample characteristics

Fifty-two Queensland community mental health service providers were interviewed by telephone during July 2014 to gather responses to questions about the three selected performance indicators for consumer participation. The only question asked about the nature of the service providers' activities was the one relevant to framing the other responses. Specifically, we wanted to know if the provision of mental health services was their primary activity or whether they primarily provided other non-mental health support to persons with a lived experience of a mental illness. An example of this would be a youth service that is not specifically funded to work with people with mental illness, but a large proportion of the young people accessing the service present with mental illness.The majority of respondents (83%) were in the business of direct mental health service provision.

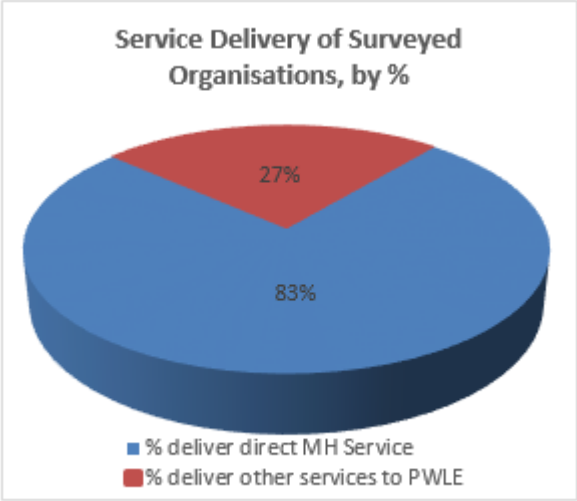


Figure 1: Service Purposes

2.b. Formal Consumer Feedback for Service Improvement

All services seek ongoing informal feedback to modify individual service delivery.Most frequent feedback is sought by services providing support to marginalized target groups such as CALD and homeless people or where service is provided on a one off or short term basis. These services were interested to explore ways to enhance feedback gathering mechanisms to contribute to organizational change.

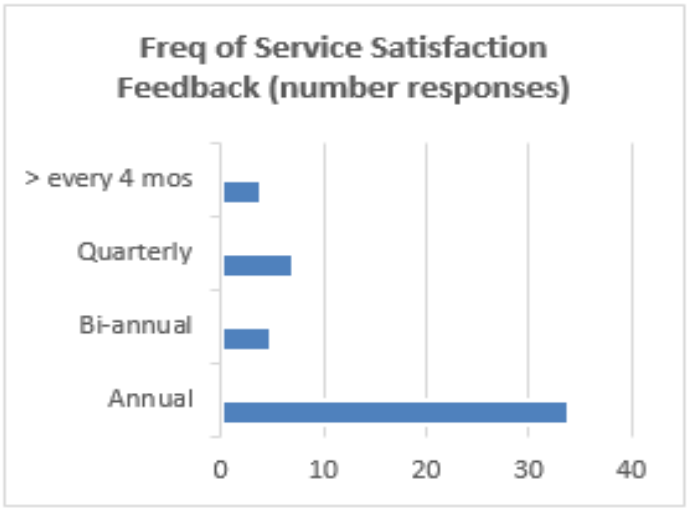


Figure 2: Frequency of Feedback

Gathering formal consumer feedback is a also a common practice among this sample, with 94% of services using some formal mechanism for surveying consumer satisfaction and other input. There is no standard survey used across the sector with organisations developing an instrument to suit their needs.There are a variety of ways this happens including written survey, verbal surveys, focus groups etc.

The majority (68%) of services do this on an annual basis. Figure 2 presents the breakdown of the frequency of this process.

The process of gathering formal feedback from consumers is well established in the sector, with nearly half of the respondents conducting this activity for five years or longer. Figure 3 graphs this distribution.

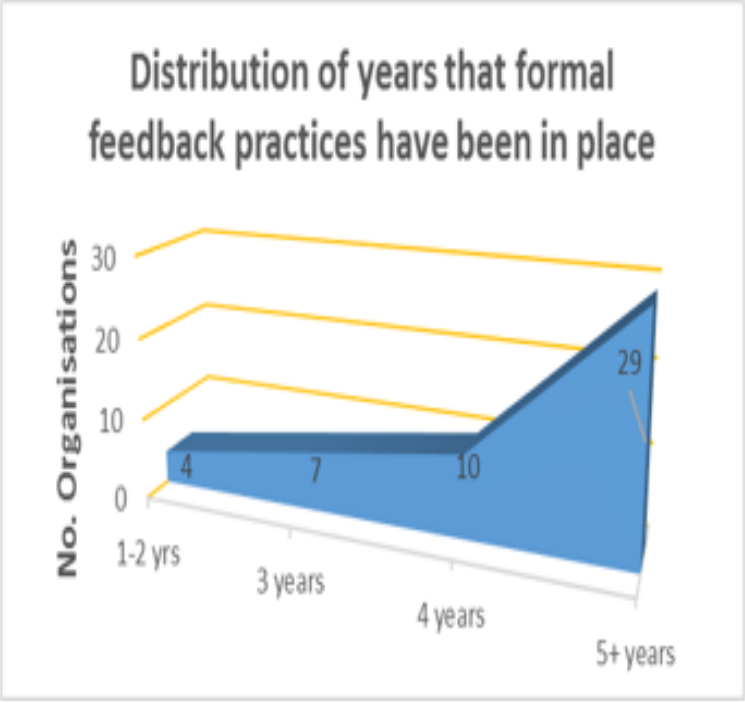


Figure 3. Length of feedback practices in operation

Approximately two-thirds of services involve consumers in the development of the survey, and slightly more than half involve consumers in its delivery. Table 1 indicates the breadth of the audiences of the survey, with the majority of recipients being staff, board and consumers.Two thirds of services report the results in their annual report and use in funding submissions.

How is feedback developed and used?							
	Yes						
Are consumers involved in the development of the survey?	65%						
Are consumers involved in the delivery of the survey?	54%	staff	consumers	board	external stake holders	annual report	fundraising submissions
Who are the results of the survey shared with?		92%	81%	90%	62%	67%	69%

Table 1: Feedback production and distribution

The most important aspect of consumer feedback, however, is the outcome: what change happens as a result. Ninety-eight percent of those services that deploy feedback mechanisms with consumers say that the feedback has an influence over organizational performance. When asked "How many service changes have happened as a result of the last survey?", less than half of the respondents (n=24) were able to identify the number of service changes.The type of changes that were articulated, in decreasing order of frequency were accessibility, activities, confidentiality, feedback/ complaints, training. Table 1a presents the distribution of the number of changes made by services as a result of formal feedback.

Table 1a. Distribution of organizational changes

	No. changes implemented as result of feedback from consumers in past year					
No. Changes	1	2	3	4	5	Unsure
No. Services	7	11	16	4	2	11

2.c. Participation in organisational decision-making

To measure services' activity in this indicator, questions were asked about the opportunities for consumers to participate in formal decision-making, how long that process has been in place, how policy provides for that activity, how consumers become involved, and what supports are available to guide consumers in this activity. Finally, services were asked how organizational decisions were communicated back to current consumers.

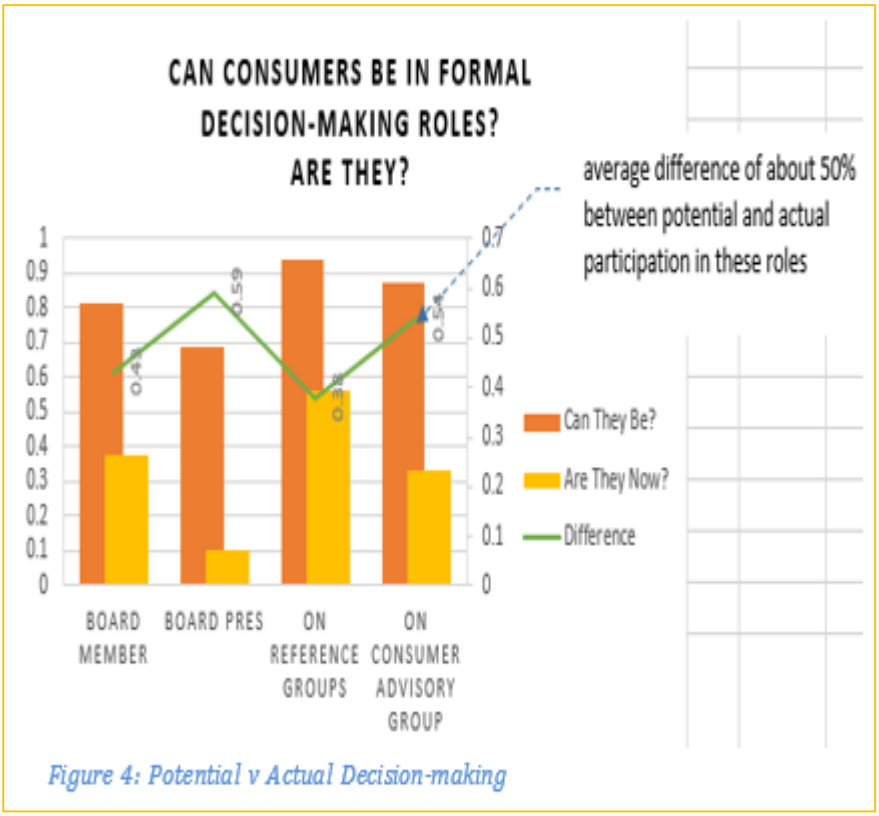


Figure 4: Potential v Actual Decision-making

Formal participation of consumers in decision-making at some level of the organization is established in the sector, with 100% of respondents claiming this as a feature of their service. Further, 60% of services have a policy that provides for some level of decision-making participation, and nearly two-thirds of respondents have had this practice in place for four or more years. The majority of services provide for consumers to self-select for decision-making roles, or combine this selection mode with consumers being selected by staff (52%), Peers (40%), or by all organizational members (44%).

More than half of the services have role descriptions, training and development opportunities for consumers involved in these roles, but fewer than half have training for people who want to emerge into these roles. This finding suggests that services do not yet use this development opportunity as a recruitment tool or as part of individual's planning, or that services default to the available training as being adequate preparation.

Consumers have long identified participation at this level as being tokenistic (Byrne, Wilson, Burke, Gaskin & Happel, 2014)[5]. The survey sought to identify which of the most typically influential roles were available to consumers, and the percentage of those roles being actually filled by consumers.

[5] Byrne, L., Wilson, M., Burke, KJ., Gaskin,CJ, Happell, B. (2014) Mental health service delivery: a profile of mental health non-government organisations in south-east Queensland, Australia. *Australian Health Review*, 38, 202–207

The findings, graphed in Figure 4 suggest an average difference of about 50% between consumers having roles on board, reference or consumer advisory groups and the availability of those roles. In about a quarter of services, there was some representation of consumers in leadership roles.

There was a striking gap though between the number of services who said decision making roles were available against the number of roles that were actually taken up by consumers. There were several reasons put forward why consumers did not exercise formal leadership in the services they use.The reasons offered for this gap include 1) consumers prefer to opt for other roles 2) these are challenging roles and present capacity issues for organisations in relation to recruitment, training and development.

Other roles for consumers were described by nine organisations: five of these saw consumers involved in staff selection, but other roles included government advocacy, fundraising, and internal quality improvement processes.

2.d. Commitment to the Peer Workforce

This survey asked about staff employed as peer workers. There is an important distinction between staff with a lived experience of recovery from mental health issues when this is not a job requirement and staff specifically employed as peer workers where it is a job requirement to acknowledge and actively draw on this experience.

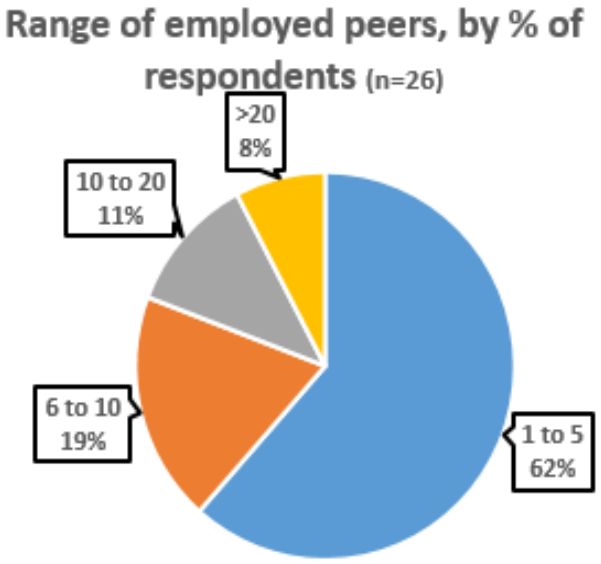
This distinction remains contentious with some in the focus group questioning whether any differentiation is an artificial barrier.The number of peer workers provided by respondents reflects the confusion surrounding the concept of peer workforce.

Among the 52 respondents, the presence of the peer workforce is becoming more established, but there are some challenges to the spread of the practice. Half of the 52 services who responded employ peer workers. Of those those who responded that they do not employ peer workers, 12% plan to begin this within a year. The remaining 38% of services do not plan on hiring peer workers for several reasons, representative responses include:

- Other peers in client group do not want peer workers;
- Substantial HR challenges for the organisation;
- Inadequate funding to resource training and development.

2.d.1. Peer Workforce Distribution:

The services that employ peer workers (n=26) employ a workforce of 267 persons with a lived experience, or a mean of 10 workers perorganisation. Presenting an average of workforce numbers distorts the overall picture since only two services employ 55% of the sample of peer workers. Figures 5 and 6 present the distribution of the workforce.



Nearly two-thirds of services that employ peer workers have, on average 3 persons in this role.

Figure 5: Percent services employing a range of peer workers

The practice of employing peer workers has been in place from four to six years for 40% of those services that engage in this process. Several respondents have been working with peers for over six years. Figure 7 presents that distribution.

Figure 7: % services engaged over time in hiring peer workers

Excluding the two services with a disproportionate number of peer workers, the average FTE of the peer workforce is 3.5 per organisation.

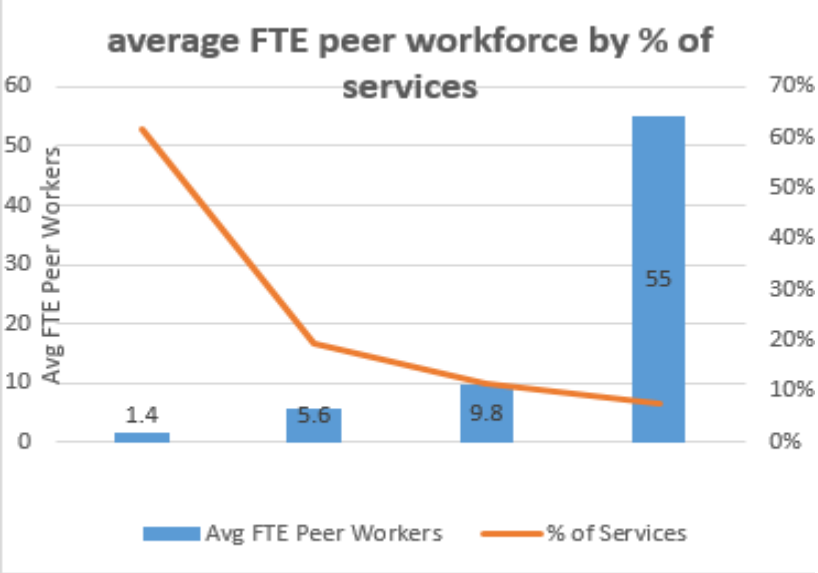


Figure 6: Avg Peer worker FTE distribution/

Despite the established nature of the peer workforce, fewer than half of the services claim to have resources or processes to support the workforce. Table 2 presents the breakdown of services that provide good human resources (HR) practices. The impact of this is discussed in Section 3: Resources Required to Develop.

Table 2:HR Practices related to peer workers	
Process to prepare service for peer workers	38%
Induction process for peer workers	37%
Specific job description for peer workers	42%
Supervision provided by a peer	23%
Policy related to peer work	35%
Practice framework that guides peer workers	40%

3. Resources Required to Develop These Indicators

The survey asked respondents what they needed to enhance the indicators of consumer participation in their service. Respondents were advised that this question was not intended as a commitment to seek to provide any stated resource, but the response was solicited purely to frame the issues or challenges the sector faces in regard to consumer participation.

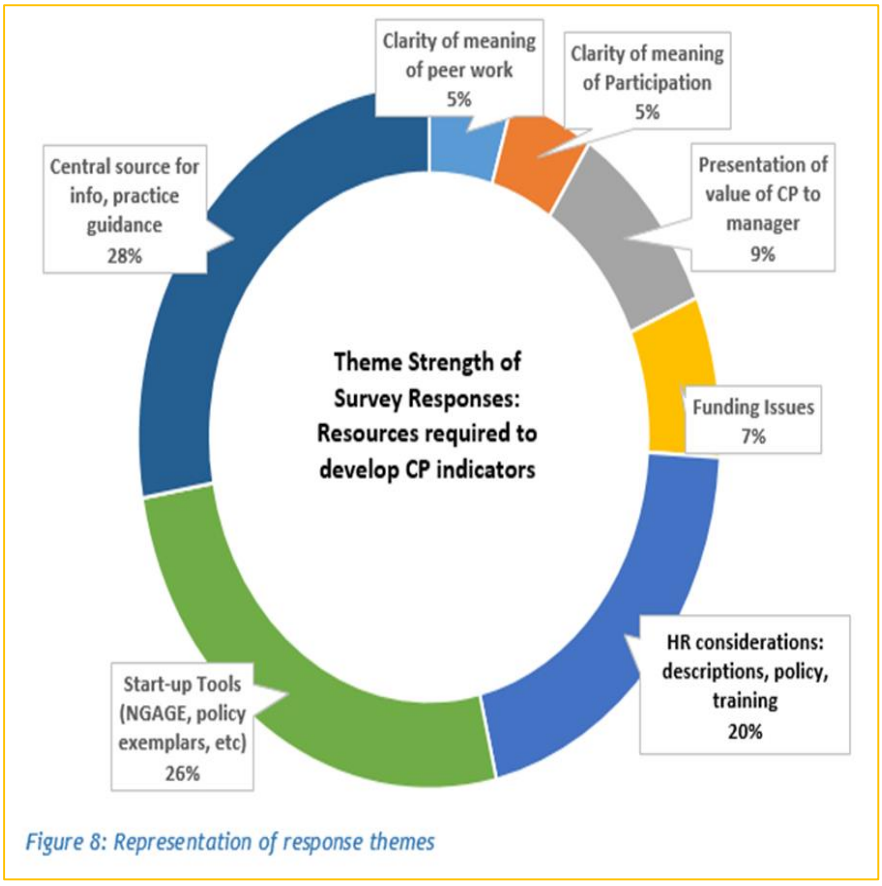


Figure 8: Representation of response themes

The free text responses to this question were analysed using lexical-chaining software (Semantria) to thematise the responses and to establish the strength of those themes. Of the 50 responses analysed, seven themes emerged.

- Three themes related to organizational strategy needs (clarity of meaning and definitional issues, sign-on and management support – particularly in larger organizations);
- The other four themes, the stronger themes, relate to operational issues: costing, training, HR requirements (policy, process, etc), start-up or development tools and an overlapping theme of a central source for guidance and information.

4. Summary

Most services are engaged in supporting consumer participation at some level but services require some guidance about policy and practice particularly in regard to developing the peer workforce.

The strongest value seems to be that services genuinely try to listen to consumers, given the strength of the frequency, duration and utility for change that formal feedback mechanisms have achieved.

Overall, there is a strong will in the sector in Queensland to move these indicators forward, at the levels of the individual consumer, the organization and to some extent, broader policy platforms. This good will and energy seems to require the following resources to nourish it:

- Networks for training;
- Resources with multiple access points, and;
- A central resource for good practice exemplars, networking, and information.

QAMH will work with members and other stakeholders to help drive change and build on the willingness to enhance consumer participation in our sector.

Acknowledgments

Queensland Alliance for Mental Health would like to thank the following people

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