


What Drives Systemic Mental Health Advocates? Goals, Strategies, and Values of Australian Consumer and Carer Advocacy Organizations

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Abstract

The consumer participation movement has growing international recognition in policy and research. Focusing on the collective context, this research systematically examines how two advocacy organizations in the Australian mental health sector are organized and motivated to advance the cause. Qualitative studies analyzed 17 strategic communication documents and nine interviews with members and staff to identify major themes relating to goals, activities, and values driving advocates and their organizations. Five major focus issues were identified: building consumer and carer participation, voice and recognition for consumers and carers, influencing and improving mental health systems, effective collaboration and partnerships, and building organizational strength. Findings demonstrate what drives consumer and carer advocates and their organizations to contribute to an organized, strong, and unified movement. While they focus on cementing genuine and effective consumer participation in health service and policy, they highly value partnerships based on mutual respect to improve mental health systems and outcomes.

Keywords

consumer participation, carer participation, advocacy, mental health, user involvement

Several large-scale social movements in mental health have emerged since the early 1800s (Bowl, 2002; Everett, 1994). The contemporary Consumer and Psychiatric Survivor Movement in the United Kingdom, the United States, Canada, and Australia began during the 1960s/1970s coinciding with deinstitutionalization and rising anti-psychiatry sentiment, but coalesced in the 1980s/1990s, building new force where change was driven by ex-patients of mental health services for the first time (Epstein, 2013; Hinton, 2009; Kaufman, 1999; Robson, 2008; Starkman, 1981/2013). Key to this movement, at least for those identifying as mental health consumers or service users (though perhaps not psychiatric survivors, see Adame & Knudson, 2007; Menzies, LeFrancois, & Reaume, 2013; for use of these terms, see Bowl, 2002; Everett, 1994), is systemic mental health advocacy, a social movement that seeks to change the disadvantageous policies and practices of legal, government, and health systems from within to develop a more inclusive community for people with mental disorders (also known as collective mental health advocacy; Stringfellow & Muscari, 2003).

Peak and local mental health advocacy organizations now exist in many countries. In Australia, there are many vocal and established consumer- and carer-run organizations who engage in advocacy and representation. Some of these groups are peak

bodies within each Australian state or territory; other organizations have a national mission (Hinton, 2009). Although they differ in specific aims and activities, systemic advocacy groups seek political and social change in mental health, especially by consumer involvement in the planning, delivery, and evaluation of policies, services, and research (Funk, Minoletti, Drew, Taylor, & Saraceno, 2006). As a result, consumer participation has received increasing political recognition: the Australian Government now recommends consumer and carer participation in the development and evaluation of health services and policy (Commonwealth of Australia, 2010). However, implementation of participation remains tied to the agenda of the political party in government. For example, in 2011, funding was provided to establish a new National Mental Health Consumer Organisation driven by mental health consumers and planned for launch in 2014. The establishment project was successfully completed, but a change of government during the

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course of the project resulted in the funds allocated to launch the organization being redirected (Mental Health Australia, 2015).

How can mental health advocacy as a social movement be sustained in the face of possible divisions between competing interests and reactions from authorities, which range from neglect to willful resistance? This is a problem of creating common cause, and our previous research in the field of mental illness stigma reduction (Gee, Khalaf, & McGarty, 2007; Gee & McGarty, 2013a, 2013b) has indicated that one way to achieve this outcome is for people with mental disorders, health professionals, and other members of the community to come to see themselves as members of a cooperative community that is working together to reduce stigma and improve the circumstances of people with mental disorders. Holding aspirations for such a cooperative community is a predictor of commitment to take action to make such a community real (Gee & McGarty, 2013a), leading Gee and McGarty (2013b) to propose that movement toward a cooperative community provides a basis for innovative bottom-up solution generation through respectful engagement (for an international application, see Lala et al., 2014).

These ideas suggest that mental health consumers can themselves be strong drivers for positive change, not just in the health and policy fields they pursue through advocacy but also in community attitudes and acceptance. We therefore set out to better understand the people behind mental health advocacy and to understand the specific activities of advocates as well as the goals and vision that drive them as a group.

The existing research literature is noticeably lacking in such explorations. Rather, the research in this area largely explores individual views or experiences of participation opportunities from consumers of mental health services and/or carers (Goodwin & Happell, 2006, 2007; Lester, Tait, England, & Tritter, 2006), from consumers with formal roles within health services (Middleton, Stanton, & Renouf, 2004; Stewart, Watson, Montague, & Stevenson, 2008), and from consumers and carers recruited through self-help and advocacy groups (Connor & Wilson, 2006; Lammers & Happell, 2003, 2004). As we have described it, however, consumer participation has developed and been molded within the broader collective and organized context of a social movement. Thus, while individual experiences and views are valuable knowledge, very little research has taken this broader view to explore the drive behind those advocating for reform through participation that leads them to act in that organized, committed, and active way.

We note two possible exceptions. Trowse, Cook, and Clooney (2012) briefly described motivations for involvement, barriers, and vision for change among 20 Australian consumer and carer members of a group actively involved in the development of a service participation strategy. Through membership in their group, participants sought changes that would improve family involvement in treatment and services,

increase workforce education that involved consumers and carers, and strengthen the consumer and carer voice in mental health. Participants were motivated by improving services and resources, helping others, and being committed to inclusion and respect of consumer and carer voices. At a broader level, Hui and Stickley's (2007) discourse analysis reveals how language in the published literature of service users in the United Kingdom reflects key issues in user involvement. Reported themes included power, change, and control (e.g., where the medical/illness model emphasizes power in favor of service providers); theory, policy and practice (e.g., frustration that service users are ignored not involved); and the value of "experiential expertise."

The reviewed research and literature highlights some of the issues around consumer and carer participation and concerns regarding mental health services and policy. However, beyond highlighting the value and desire to increase consumer/carers participation (and the challenges of doing so), it has not specifically explored or detailed what advocates want to achieve or the ways they are working to achieve it. In this article, we report qualitative research that specifically and systematically examines how two advocacy organizations in the Australian mental health sector and their members and staff are organized and motivated to advance the cause. We examine key documents of the organizations and interviews with members and staff to understand what drives advocates; specifically, the vision that drives them and the goals, activities, and values communicated by them and the systemic organizations they belong to.

Method

Data Collection

We collected data in two organizations. The first organization was a consumer-run state-based group. The second, established by the Australian Government, consisted of consumers and carers. Both received government funding (state and national government, respectively) and were operating more than 7 years. Research was conducted in consultation with members and staff over 12 months. Approval was obtained from the university's Human Research Ethics Committee and staff, members, and governing committees of each organization.

We sought data from two source types: organizational documents and interviews with key members and staff. Documents were sought to explore how the organizations themselves prioritized and described the work they do. That is, how the official organizational documents were used to detail their work and how they had chosen to communicate their organizations, their people, and their work to others. In addition, we sought interviews to explore how the people themselves described their experiences as advocates and what drove them in their commitment to the cause. We expected interviews to provide more anecdotal and

experiential information that may not be included in the more formal documents. Therefore exploring these sources together would reveal a more complete overall picture of the advocates' work, their goals, and their aspirations.

Documents from 12 months preceding the studies were analyzed (2008-2009). These were organizational documents (operating procedures/guidelines, annual reports, strategic plans) and key communications to the public (brochures, newsletters, online biographies). A total of 17 documents were included: six from the consumer-run organization (one newsletter), and 11 from the consumer and carer group (five newsletters). The purpose of analysis was to identify key focus issues for the organizations, as communicated to their members and stakeholders, and the goals, activities, and values advancing that focus.

One-to-one interviews of 25 to 65 minutes were conducted by the lead author at the organization's offices or by telephone with nine governing or long-term members and staff, who volunteered to participate and provided written consent. All had been with their organization for 2 to 7 years ($M = 3.8$ years). Interview questions were purposefully broad: (a) "what is the organization working to achieve?" and (b) "what kind of community is the organization aspiring to?" Further prompts encouraged interviewees to expand on their responses. This article reports how advocates define their vision and drive. We report elsewhere findings on the advocates' perceived helpful relationships in mental health reform (Gee & McGarty, 2013b).

Data Analysis

A thematic analysis (Liamputtong & Ezzy, 2005) with inductive coding was used. In Step 1, initial coding of each organization's documents grouped similar themes for goals (statements reflecting broad/specific organizational aims, purpose, objectives, vision, or strategies), activities (specific actions or general roles, planned, underway or completed), and values (often in content describing goals and activities). Content was coded to a single goal or activity; this same material could also be coded to a value. Once the coding structure emerged, documents were again analyzed to ensure the structure reflected the content of the documents and ensure consistency. In Step 2, findings for both organizations were compared and combined to identify common main themes. In Step 3, interview transcripts were coded by theme. The emerged structure was cross-referenced with document analyses. Interview content was highly consistent with documents and provided richer examples of themes identified in documents and provided more context for work described in documents. Findings that emerged during analyses were discussed across the research team at various stages of the analysis.

As part of the ongoing collaboration process, each organization was given a draft report describing the findings specific to their respective organization and invited to provide feedback. Both organizations provided feedback and neither

suggested changes to the findings or themes described. A copy of the manuscript reporting the combined analyses was also provided to both organizations for their feedback and approval prior to original submission. Again, no suggested edits regarding the findings or reported themes were offered.

Findings

Overall, document and interview content reflected five major themes. These themes and extracts illustrating them are provided below with a unique identifier revealing the document source (D1-D17) or participant (P1-P9) and whether the source originated from the consumer-run (O1) or consumer and carer (O2) organization.

Building Consumer and Carer Participation

Organizations aimed to build participation in decision making at all levels (policy and service development, implementation, delivery, review, and reform) and develop the use of lived knowledge and experience. One interviewee described the various forms for this:

They [could] approach . . . directly and ask for appropriate people to be provided to be that voice and representation . . . be it a 10-minute once-off timeslot in a training seminar for doctors or be it a long-term consultant process of a committee that's formulating professional development or other kinds of things here in Australia. Some of the government departments that make decisions that directly affect mental health carers and consumers are supposed to have consumer and carer representatives involved in those decision-making and they actually don't unless we demand it, and even then we can't always get involved at a level where that voice is respected . . . In terms of . . . [local and state government] areas, I suspect around the majority of Australia it's still not considered the natural course of events that one would consult, and I think that there is ignorance that there is that kind of voice even available at a level that should be respected. (P1O2)

The advocates sought consumer and carer participation primarily through representation and lobbying, as well as having consumer and carer representatives on committees, producing submissions, and meeting with constituents, government departments, and ministers. They facilitated this through training for members (e.g., advocacy, media skills, communication, conflict resolution) and by providing mutual support (e.g., administrative support, debriefing, attending committees in pairs). These activities strongly reflected the values of consumer and carer knowledge and experience as an important resource; of building and accepting opportunities for genuine input and participation; and, for the consumer-run organization, dignity, pride, and empowerment for consumers.

We're basically an advocacy group, a systems advocacy, so we look for things in the system that are wrong and try to put a

consumer perspective to it, and generally we try to get committees to include consumers . . . [P4O1]

There wouldn't be a system without the consumers . . . we have to go from the current situation which can often be about a sense from providers—probably also political perspective . . . [of] providing this service for these people, and . . . this sense of well they should blimmin' well be *grateful* [inflection] . . . [P5O1]

We have, thanks to the Human Rights Act, no excuse for allowing ourselves to pick up crumbs from the plate and then to tip our hats and say thank you. We will one day (soon, I hope), be able to say "This is what I want, when can you deliver?" That would be Great!! [D5O1]

Voice and Recognition for Consumers and Carers

The importance of presenting a unified voice for consumer and carer issues and concerns was also emphasized. Advocates aimed to present unity to contribute to better recognition of consumer and carer concerns and raise awareness of these among professional bodies, government, and the community. Importantly, this unity must also allow for the representation of the diversity of views across members where such diversity arose, whether across individual members such as in transcultural mental health or across different views of consumers and carers.

[Having a united perspective] doesn't mean that we aren't diverse and . . . we don't have differences, it means that we come to agreement, so our diversity and our different perspectives and our different levels of training and skills that we all bring, different backgrounds and professional training that we've all had in our own areas of professional life and expertise, we bring all of that to the table. [P1O2]

For the advocates, such unity in voice was vital to improve the recognition of consumer and carer concerns and raise awareness of these among professional bodies, government, and the community. The organizations valued inclusive practices, being an independent voice and being informed. They were also driven by the value that their experience could offer (e.g., "unique consumer perspectives" [D1O1], "utilise our lived experience and unique expertise in mental health" [D4/D5O2]). Activities such as consulting with members and the wider mental health community to identify issues of concern, defining the consumer/carer position, seeking input on projects, and being accountable to members were all targeted toward presenting a unified voice for consumer and carer issues.

Influencing and Improving Mental Health Systems

The organizations aimed to influence decision making and change to improve mental health and health services, policies,

and practices according to the needs of consumers and carers. They worked to ensure that services and practices uphold the rights of people with mental disorders and are consistent with social justice values (human rights, equality, inclusion).

In terms of being directly involved in systemic advocacy, influencing legislation, that kind of thing . . . I believe all of us want to . . . promote and progress the recognition and inclusion of mental health consumers and carers at all levels of government and community particularly in policy-making. [P1O2]

Social justice is the backbone of consumer advocacy and is based on . . . rights, equity, access and participation. [D4O1]

In communities that are switched on to the health care agenda if you like . . . I and a number of other people consider the right to be involved in the type of services we receive is an inherent right. Australia doesn't do rights terribly well." [P2O2]

Associated activities were again representation and lobbying, and educating and informing community, non-government and government organizations about consumer and carer perspectives by presentations at meetings, conferences, lectures to university students, and media interviews. A large number of references in documents and interviews related to this theme, and these were embedded within broader quotations and documents. For example, many such references were presented as one-line pieces of information within other stories, such as referring to the goals of advocates and the organizations or referring to specific examples of representation, projects, or input they had provided. Overall, the number and degree to which these references were embedded indicated that this work attracted a large proportion of the advocates' time and was seen as one of the core areas of focus.

Collaboration

Building collaborations with other community, government and non-government organizations, professionals, bureaucrats, and service staff was important, including reporting to stakeholders and constituents. Partnerships reflecting the values of listening, respect, and cooperation were developed through activities such as seeking the support of other bodies, distributing information through networks, reporting to partners, attending meetings, and building associate memberships.

. . . in order to achieve the kinds of purposes we have . . . I believe it takes a strengthening and developing of partnerships with stakeholders and organisations, with relationships with different sectors of the government . . . if you have some relationships within that framework and understanding and respect then that carries some influence into a national picture. [P1O2]

A deeper exploration of the advocates' views on the type of collaboration and partnerships needed in advancing mental health reform is reported in Gee and McGarty (2013b).

Building Organization Strength

Sources referred to the importance of the organizations to act in responsible, professional, and ethical ways. They conducted membership reviews, promoted the organization, and engaged in good business practices to “be a proactive, responsible and sustainable organisation in regards to financial, employment, volunteer and work culture practices (good practice)” [D3O1]. Sustainability was also emphasized along with the need to build stronger organizational profiles (e.g., a “stronger,” “sustainable,” “established” organization [D2O1] that was “building its own capacity” [D7O2]). References to this theme occurred less frequently and were largely restricted to official documents. However, it was clear that building organizational strength and sustainability were seen as important in continuing the work of the advocates and in building and maintaining a strong reputation as an influential source for mental health reform.

Discussion

Findings reveal key goals, activities, and values underpinning the work of consumer and carer advocates of two Australian systemic advocacy organizations. Advocates were driven to build consumer and carer participation, increase voice and recognition for consumers and carers, and influence and improve mental health systems. They sought to do this largely through activities such as representation and lobbying; seeking to demand, provide, and support consumer and carer representatives on (largely) health and government committees; and collaborating and building partnerships with other organizations, professionals, and government.

Findings are consistent with literature describing the rise of the consumer participation movement (e.g., Bowl, 2002; Everett, 1994). While previous qualitative research exploring participation has interviewed individual consumers and carers, and thus largely focused on participation as collaborative care planning and treatment, the current research offers an alternative approach to explore consumer participation in the context of mental health systemic advocacy. Rose (2014) describes the transition of what was originally a consumer-driven group movement about recovery into mainstream health services, where the original concept appears to have been taken and ultimately molded into a very individual concept. She implies that this shift from the group-level consumer identity to a focus on consumer individuals has resulted in reduced power in the consumer movement. Questioning the representativeness of consumers, as described by Happell and Roper (2006), is another example of this. By focusing on individual experiences of individual consumer consultants, these advocates are disempowered in their role and disconnected from the social group identity. Perceived as individuals, their experiences are judged to be atypical or unrepresentative of the group they identify with, and their opinions are therefore considered to be easily dismissed.

We wonder whether, by focusing largely on interviews with individual service users, previous research is another example of such a process. In influential contemporary sociological perspectives, individualization emphasizes personal choice, freedom, and agency and downplays the broader structure or social context, often missing the role that social disadvantage plays in limiting the available opportunities from which to choose for some groups of people (Brannen & Nilsen, 2005). This individualization focus has methodological implications (Brannen & Nilsen, 2005): If empirical explorations are designed and analyzed through this lens, even implicitly, then these individual understandings will inform the knowledge gained from research.

A related point is the issue of language. Some have argued that adoption of the term *consumer* to refer to people with mental disorders has been problematic for this group because it positions mental health advocacy as an individualized excrescence of neoliberalism (Brannen & Nilsen, 2005; Holdsworth, Sweeney, & Pollard, 2004). First, the term *consumer* is used to indicate (desirable) personal agency in power, freedom, and choice over engagement in services (Brannen & Nilsen, 2005), and adoption of this term was probably, at least originally, intended to place more power for mental health advocates to have a say in the services offered. However, not all people involved in the mental health service are willing, and many also do not have the financial means or power for free choice (Holdsworth et al., 2004); thus as a group, their disadvantaged status entails that they do not have the economic bargaining power and capacity to influence services that purchasers of other goods and services have (or are imagined to have). Thus, the focus on individual choice over group disadvantage is an example of individualization. Second, the shift toward individual agency and choice transforms services from being entailed as the rights of citizens to being options that consumers have the responsibility to seek out. In turn, governments and other service providers are absolved of the responsibility to address their citizens' needs (Holdsworth et al., 2004). The uptake of the term *consumer* may be a tactical mistake for mental health advocacy.

Regardless of these micro-sociological contentions around use of the term *consumer*, in social psychological terms the mental health advocacy movement (or the consumer movement) can be understood as an opinion-based group (Bliuc, McGarty, Reynolds, & Muntele, 2007; Bliuc et al., 2015; McGarty, Bliuc, Thomas, & Bongiorno, 2009) in that it captures a social identity around the shared opinion that people with mental disorders should not be discriminated against and that united socio-political action is required to overcome this disadvantage. The mental health advocacy movement therefore can function as a *powerful, group* identity. Rose (2014) argues that a shift back toward the group identity is needed to advance group-level change. In contrast to the existing research exploring the experiences of individual consumers and carers, our current study brings the

collective back into focus, having systematically explored and documented the drive and work of advocates in their own words and the way this is communicated by their organizations.

In this article, we have therefore deliberately adopted the term used by advocates themselves and referred to people engaged in the advocacy movement or mental health services as consumers. Thus, findings are relevant in particular for those advocating for consumer participation (or user involvement) or who identify with this term. The term *psychiatric survivors* is a front-runner alternative, referring to those who seek liberation from mental health service and psychiatry in particular, rather than to reform mental health services and policy through participation (Everett, 1994). Using this distinction, our research does not explore the views of psychiatric survivors. Current findings do, however, identify the values of dignity, pride, and empowerment for the consumer-run organization, which have a strong connection to the driving force behind psychiatric survivor perspectives.

One finding emerging from the current research that has not been described in the existing literature is the organizations' focus on building organizational strength, profile, and sustainability. In defining these, staff and members sought to maximize their effectiveness and longevity in progressing reform and consumer/carer participation and accurately and fairly representing the often diverse views of members. Thus, they are contributing to an organized, strong, and unified movement as outlined by others (Everett, 1994; Starkman, 1981/2013), but while also recognizing that consumers and carers as a whole are a diverse group (Lammers & Happell, 2003).

Findings identified values that typically related social justice principles, which many consumers and psychiatric survivors have observed to be lacking in services: human rights, equity, and inclusion for people with mental illness. Service users have also reported feeling misunderstood and disempowered in seeking help (Anderson, Fuhrer, & Malla, 2013) and high levels of dissatisfaction (Morgan, 1999). Involving consumers and carers in the development, delivery, and evaluation of health services can address identified shortcomings and provide input to develop services that meet the outcomes valued by consumers, carers, and staff (Lasalvia et al., 2012). In addition, the advocates and organizations in the current research strongly valued partnerships and collaborations grounded in listening and cooperation. They actively sought to work *with* government, professionals, and others in genuine and respectful relationships.

The current research sought to better understand the group of people behind mental health advocacy by exploring how the advocates and the organizations themselves described the goals, drive, and activities behind the work they do. One limitation is it was conducted with a small number of participants from two well-established organizations in receipt of government funding. While findings may not generalize to other organizations, interviewees had dedicated several years to these groups and both organizations aimed to represent diversity among consumers and carers.

From listening to these advocates in these interviews, it became clear that mental health advocacy and representation work can be very challenging, especially in the health and government domains, and that at times consumer and carer advocates have had experiences where they appear to have been treated as a nuisance by those in power. This research shows that as a group, consumer and carer advocates are dedicated, skilled, and respectful. While their focus is to demand participation and challenge existing systems, they equally seek partnerships based on mutual respect. Understanding people with mental disorders within this context of a shared group identity where they are active, organized, and driven may be a useful tool in challenging the negative stereotypes that contribute to stigma (Gee et al., 2007). In this article, we have documented the work and the drive behind this group of people, and we see this as an important step in being able to educate students, trainees, health professionals, and the public using this type of information to reduce stigma.

Advocacy organizations have been upfront about their goals and aspirations and these are made transparent in the findings of this article. It now calls upon others in positions of power in mental health service and policy to accept the call and themselves to participate in genuine relationships of mutual respect and partnership with consumers and carers for the advancement of mental health.

Authors' Note

The information and opinions contained in it do not necessarily reflect the views or policy of the Australian Primary Health Care Research Institute or the Australian Government Department of Health and Ageing.

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