

Consumer-run services research and implications for mental health care

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Mental health consumers/survivors developed consumer-run services (CRSs) as alternatives to disempowering professionally run services that limited participant self-determination. The objective of the CRS is to promote recovery outcomes, not to cure or prevent mental illness. Recovery outcomes pave the way to a satisfying life as defined by the individual consumer despite repetitive episodes of disorder. Recovery is a way of life, which through empowerment, hope, self-efficacy, minimisation of self-stigma, and improved social integration, may offer a path to functional improvement that may lead to a better way to manage distress and minimise the impact of illness episodes. ‘Nothing about us without us’ is the defining objective of the process activity that defines self-help. It is the giving of agency to participants. Without such process there is a real question as to whether an organisation is a legitimate CRS or simply a non-governmental organisation run by a person who claims lived experience. In considering the effectiveness of CRSs, fidelity should be defined by the extent to which the organisation’s process conveys agency. Unidirectional helping often does for people what they can do for themselves, stealing agency. The consequence of the lack of fidelity in CRSs to the origins of the self-help movement has been a general finding in multisite studies of no or little difference in outcomes attributable to the consumer service. This, from the perspective of the research summarised herein, results in the mixing of programmatic efforts, some of which enhance outcomes as they are true mutual assistance programmes and some of which degrade outcomes as they are unidirectional, hierarchical, staff-directed helping efforts making false claims to providing agency. The later CRS interventions may provoke disappointment and additional failure. The indiscriminate combining of studies produces the average: no effect.

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Mental health consumers/survivors developed consumer-run services (CRSs) as alternatives to disempowering professionally run services that limited participant self-determination. Proponents hold that these services for persons diagnosed with serious mental illness effectively empower their members in a fashion that promotes recovery and are a major component of the mental health system (The President’s New Freedom Commission on Mental Health, 2003). CRSs are likely to play an increasing role in the treatment plans of all individuals seeking service in public mental health systems throughout the world (US Department of Health and Human Services, 1999; WHO, 2001, 2008; SAMHSA, 2011). In 2008, funding was available for associations of service users or consumers in most of the EU15 countries. In the USA alone, the Center for Self-Help Research’s (CSHR’s) collaborative survey

with the National Association of State Mental Health Program Directors (NASMHPD) showed that, in 1993 (Segal, 1994), 46 states were funding 567 such organisations; by 2015 a similar survey compiled a sample frame of 895 (Ostrow & Leaf, 2014). Directors of 190 CRSs tended to view their services as alternatives to traditional mental health services (Ostrow & Hayes, 2015). Programmatically, CRSs offer an array of participatory opportunities including: drop-in, self-care classes, WRAP and mutual support groups. They also engage in advocacy, anti-stigma initiatives and committee participation. CRS as an organisational descriptor includes organisations that feature the role of consumers helping each other as integral to their mission. Participants can help themselves and each other through peer support, power sharing and client control of services (Zinman, 1987). Zinman (1987) defines the essential characteristics of a CRS as client control of all programme aspects with autonomy from the mental health system; voluntariness of all services; emphasis on addressing the economic, cultural and social needs of members; and sharing of power within a structure that seeks to minimise hierarchical relationships.

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Helping oneself, and being part of a group of individuals with similar issues who are working together to help themselves, fosters a sense of mastery and is probably one of the most satisfying human experiences. It is hard to replicate the gratification it seems to provide to people with mental illness who have experienced repeated and significant hardships; gratification evidenced by the changes in facial expressions and posture during such participatory experiences. Participation in such services can thus be a gift made possible by finding a position where one, on their own, in a group, or in an organisation, can make decisions that are respected and implemented; people can participate in a meaningful way that provides a context of self-respect for the result of their decision-making process. It is extraordinary to understand that one's disability in such a context is not only accepted, but a qualification for participation. The achievement of such positive effects is owned by the individual, not by the helper. Thus, the rule for fidelity of self-help intervention – i.e., whether the intervention is truly self-help – is based upon the extent to which the individual is involved in their own decision-making or the decision-making of a group or organisation in which they are involved, and the extent to which that decision-making can contribute to implemented action. Whether the self-help intervention is effective is measured by the extent to which participation in decision-making leads to measures of positive outcome. However, clinical trials focused on the contributions of CRSs in mental health have yielded mixed outcomes (Lloyd-Evans *et al.* 2014). Herein the focus is on CRS organisational process and structure, how these influence service outcomes and how the research and the mental health services communities should consider these differently to achieve and document more evident positive outcomes.

Founders ideology

'Nothing about us without us' is the defining objective of the process activity that defines self-help in California. It is the giving of agency to participants. Without such process there is a real question as to whether the organisation is a legitimate CRS or simply a non-governmental organisation run by a person who claims lived experience. In considering the effectiveness of self-help activities, intervention fidelity should be defined by the extent to which the process conveys agency. The outcome should be criteria-defined as those discussed among self-helpers, and include empowerment, hope, self-efficacy, functional enhancement and reduced symptomatology. Interventions calling themselves self-help enable people to help themselves, but most importantly do not do things *for* people that they can do for themselves, thereby stealing agency.

CRSs, though founded on the principles of self-help, are not all self-help services, and their essential components are poorly defined in the literature. Generally, mental health research has failed to make the distinction between those with fidelity to the self-help approach and those that are simply run by individuals or organisations who employ a former patient/consumer. Even the definition of who is eligible to be a consumer, one with lived experience, has blurred from an original criterion of inpatient hospitalisation, to an unspecified outpatient contact, to a member of an underrepresented minority. In the face of vague definitions and funding mandates requiring consumer participation, organisations define their own version of consumer-led services and peer support with little specification of what consumer-providers actually do or the model of lived experience they are supposed to represent. Some reviews of peer support specifically exclude CRSs and have eliminated the 'lived experience' criterion from the core definition of peer support, defining it no differently from generic social work: 'a system of giving and receiving help founded on key principles of respect, shared responsibility and mutual agreement of what is helpful' (Mead, 2003, as cited in Repper & Carter, 2011, p. 394). Repper & Carter (2011) acknowledge a problematic shift from reciprocal peer relationships to less symmetrical ones, noting that 'where peers are employed to provide support in services, the peer employed in the support role is generally considered to be further along their road to recovery (p. 395)', and that such a shift underlies the diverging roles of peer support within unique service modalities, from mutual support group members to peer support workers (PSWs) in mental health systems (Davidson *et al.* 1999; Repper & Carter, 2011).

The consequence of the lack of fidelity to the origins of the self-help movement has been a general finding in multiple meta-analyses and some multisite studies of no or little difference in outcomes attributable to the consumer service (Lloyd-Evans *et al.* 2014), or when focused on randomised control trials (RCTs), inconsistent findings (Doughty & Tse, 2011; Repper & Carter, 2011). This, from our perspective, results from mixed programmatic efforts, some of which enhance outcomes as they are true self-help programmes and some of which degrade outcomes, for in the false claim of providing agency comes disappointment and another failure. The indiscriminate combining of studies produces the average: no effect, or inconsistent effects that support CRS by relying on failure to report significant differences, i.e., inappropriately accepting the null hypothesis.

What seems necessary is research that focuses on engagement of consumers in self-help interventions since there is no reason to believe that most, if not

just a few, are able to effectively carry out such a task. Yet, many CRSs become useful to financially troubled mental health systems as a source of cheap care; PSWs serve as a proxy for professionally led services the system can no longer afford to provide. There needs to be a more focused understanding of CRS outcome objectives to enable researchers to better choose appropriate criterion variables.

The recovery objective, mental illness and CRSs

The objective of CRSs as understood at the Center for Self Help Research (CSHR), an organisation of consumers and researchers, was not to cure mental illness. Nor was it to promote prevention of illness recurrence; rather, it was to promote recovery – i.e., to pave the way to a satisfying life as defined by the individual consumer despite repetitive episodes of disorder. Recovery, as a way of life which through empowerment, hope, self-efficacy, minimisation of self-stigma and improved social integration, may offer a path to functional improvement that may lead to a better way to manage distress and minimise the impact of illness episodes. At the CSHR, we cooperatively worked with CRSs to agree upon outcome objectives. The aforementioned components of recovery were the cooperatively chosen outcome criteria against which we concluded the effectiveness of CRSs should be assessed. The consumers on our staff helped identify these components and their lived experience was believed to contribute to a mutual effort to achieve recovery.

Recovery-focused services at the CRSs we worked with were not focused on curing mental illness or preventing recurrent episodes. They focused on minimising coercive intervention and worked to minimise the impact of such service on living a satisfying life. Lived experience for some involved the rejection of the definition of *Being Mentally Ill* as in the adoption of Scheff's (1970) sociological understanding of the path to being labelled as such; for others there was an accommodation of the medical perspective of mental illness but an acceptance of Scheff's path to social dysfunction as defined by Gruenberg's Social Breakdown Syndrome (1966); others accepted mental illness, with psychology's perspective, as an aggregation of dysfunctional behaviours, analytically or behaviourally defined; while others embraced DSM's syndromal definitions. Thus, as understood at CSHR, CRSs were less about the definition of mental illness and more about recovery. In accordance with philosophies driving CRSs, these services were about improvement of one's ability to live a better life with the cards they had been dealt.

Research design

Having specified recovery objectives and selected research outcome criteria, the nature of the CRS service organisation needs specification. At CSHR we considered CRSs that were explicitly mutual support in character, groups and organisations where interactions were reciprocal in nature, even if some participants were viewed as more experienced or skilled than others. CRSs were run by and for consumers in groups and when in organisations they were required to have a consumer director, a board of at least 50% consumers, and the ability to hire and fire professionals in the organisation. The latter organisations needed a specified mechanism, usually a community meeting, to enable mutual decision-making and to equalise hierarchical unidirectional decision-making. Unlike the classification used by the recent Lloyd-Evans *et al.* (2014) meta-analysis of the effectiveness of peer support for people with mental illness, we considered unidirectional service provision either in organisations that offered peer delivered support or where such service was delivered by PSWs employed in traditional mental health service agencies as a primarily resource/money-driven endeavour. Such services employ untrained individuals, less schooled in therapeutic techniques than professionals, to do their best to help, relying on their personal charisma and lived problem solving experience – good or bad, but usually unspecified – as their primary tool. We find little reason as to why such service should be effective. Though some have suggested such service helps via social learning – modelling what is possible for people in recovery – or as a matter of increased trustworthiness. Positive outcomes may not be due to specialised training, but attributable to the nature of the helper, in which case the ability to engage is a central characteristic facilitating the outcome, not lived experience *per se*. The core component of CRS effectiveness would benefit by research investigation of these suggestions.

The CSHR model

CSHR was conceived as a vehicle that would enable the research and service community to come to a better understanding of the effective components of CRS provision. Initiated at the request of consumer leaders, this joint effort between researchers and consumers focused on programme evaluation and the discovery of the essential ingredients of effective CRSs. The CSHR research programme is described herein in summaries of four papers. These research evaluations are a model in that they employ recovery outcome criteria, enable consumers to describe the service environment of their CRS and thus to empirically distinguish

between the CRSs that offer a mutual support programme from the organisations that, while meeting the administrative criteria defining a consumer-run organisation, are actually top-down, unidirectional service providers and perceived as such by their service users. The papers are a model for researchers needing to validate the distinction between organisations that provide mutual support and those that provide unidirectional service; they offer a battery of recovery-focused outcome measurement, and in multisite RCTs involving paired CRS and traditional community mental health service providers demonstrate the potential consequences of failing to make a distinction between these types of service organisations.

The literature on CRSs distinguishes two organisational types based on their leadership style. The first is an organisation emphasising mutual supportive decision-making; we have called this the self-help agency (SHA). The second type, referred to as a board-staff-run CRS, is one relying on unidirectional decision-making. This study considered whether the characteristics of these two organisational leadership styles were recognised by members and whether these characteristics are associated with membership degree of empowerment on four selected recovery measures: self-efficacy, personal empowerment, organisational-mediated empowerment and extra-organisational empowerment. Two hundred and fifty new entrants to five CRS drop-in centres rated the programmes' leadership style using the COPEs System Maintenance Sub-Scales of Order and Organisation, Program Clarity and Staff Control. These members also assessed their own status on the four aforementioned recovery measures. CRS system maintenance differences in mutual *v.* unidirectional decision-making significantly distinguished the two organisational types. Mutual support agency members scored significantly better than members of unidirectional decision-making programme members on three of the four empowerment measures. Mutual support organisations' emphasis on involved decision-making and power sharing between designated staff and non-staff members appeared to more effectively use organisational decision-making processes to empower their members.

The SAMHSA multisite CRS study used CSHR's organisationally mediated empowerment scale (OMES) and reported OMES scores among the eight sites in the study as generally 'quite low' (Rogers *et al.* 2007) with 'an overall negative effect on [OMES scores] over time' (Rogers *et al.* 2007, p. 792). Possibly the modest effects reported by the SAMSHA study in its empowerment measures were driven by the presence of CRS sites run more in conformity with a top-down unidirectional decision-making model than a mutual support decision model. The SAMHSA

multisite report actually noted considerable site variation in OMES scores but tended to attribute this to programme content differences rather than the absence of an essential ingredient – a true mutual support method of power-sharing in agency decision-making – in some of its sites. Such site variation in mutual support decision-making may have accounted for their failure to find a significant improvement over time in OMES scores. It may imply that some sites did not use their organisational context to empower their membership (Rogers *et al.* 2007).

This assumption was tested in the CSHR multisite clinical trial reports. CRSs managed to promote mutual support via shared decision-making and CRSs that were hierarchically organised to afford unidirectional services were studied as potential additional components of service in working jointly with community mental health agencies (CMHAs) to promote recovery-focused outcomes. The first study considered the joint efforts of mutual decision-making CRSs and CMHA services in assisting recovery for persons with serious mental illness. New clients seeking CMHA services were randomly assigned to regular CMHA services or to combined CRS-CMHA services at five proximally located pairs of consumer-run drop-in centres and county CMHAs. Member-clients ($N=505$) were assessed at baseline and at 1, 3 and 8 months on five recovery-focused outcome measures: personal empowerment, self-efficacy, social integration, hope and psychological functioning. Overall results indicated that combined CRS-CMHA services were significantly better able to promote recovery of client-members than CMHA services alone. The sample with combined services showed greater improvements in personal empowerment, self-efficacy, and independent social integration. Hopelessness and symptoms dissipated more quickly and to a greater extent in the combined condition than in the CMHA-only condition. The member-empowering CRSs run as mutual decision-making organisations in combination with CMHA services produced more positive recovery-focused results than CMHA services alone (Segal *et al.* 2010).

The second trial considered the efforts of a CRS – where services as noted above had been described by members as hierarchically organised and decision-making unidirectional – in concert with CMHAs. This study's objective was to again determine the effectiveness of such combined services for people with serious mental illness. The procedures mirrored the first trial. Client-members were assessed at baseline and three follow-up points on the same recovery-focused outcome measures. Results indicated that significant changes in three outcomes were associated with service condition across time: social integration, personal empowerment and self-efficacy. All changes

favoured the CMHA-only condition. Neither symptomology nor hopelessness differed by service condition across time. Further, the CMHA-only outcomes did not differ from those obtained by the CMHA-only participants in the previous trial. It thus appeared that CRSs employing unidirectional decision-making procedures may be less helpful than CMHA service alone (Segal *et al.* 2011).

In a subsequent analysis of the same two trials' data an additional recovery-focused criterion was considered. Again, CRSs with mutual decision-making procedures combined with CMHA service was compared to CMHA service alone and a CRS with unidirectional helping combined with CMHA was compared to CMHA service alone to assess the contribution of the different CRS types in reducing self-stigma. The CRS mutual decision-making model combined service experienced a greater positive effect on self-stigma scores than the CMHA-only participants, a result attributable to participation in the combined condition. The combined conditions also evidenced a greater positive effect on organisational empowerment. The CRS members of the unidirectional programme combined with CMHA participants experienced a greater negative effect on their reported self-stigma than CMHA-only participants, again a result attributable to participation in the combined service. In the CRS trial of the mutual decision-making-CMHA, participants showed positive change in self-efficacy, whereas the change among the CRS uni-directional-CMHA participants was negative. Differential organisational empowerment efforts in the CRS-mutual decision-making programme and the CRS-unidirectional programme appeared to account for the differing outcomes. Members experienced reduced self-stigma and increased self-efficacy when they were engaged in responsible roles (Segal *et al.* 2013).

Empowerment as shared decision-making

'Empowerment' has become part of the mental health lexicon. In general, it signifies a process by which individuals with lesser power gain control over their lives and influence organisational and societal structures within which they live. In the context of community services, the exercise of power implies the 'ability to get what one wants, and the ability to influence others to feel, act and/or behave in ways that further one's own interests' (Dodd & Gutierrez, 1990). It is 'the capacity to influence the forces which affect one's life space for one's own benefit' (Pinderhughes, 1983, p. 332). Empowerment, then, connotes both a process and an outcome; as consumers gain power to obtain resources on multiple levels, they are enabled to gain

greater control over their environment (Hasenfeld, 1987). For persons with serious mental illness, such a process may include gaining through their own efforts new resources or competencies such as the capacity to help others, group leadership skills, organisational leadership abilities and influence in the civic and political spheres (Zimmerman & Rappaport, 1988; Rappaport *et al.* 1992). Mental health service providers have generally adopted 'empowerment' as a programme principle in recovery-focused services geared towards meeting the needs of people with mental illness. These services may include programmes designed to increase social skills, client decision-making in programme operations and supportive peer interactions (Berman-Rossi & Cohen, 1988; Cohen, 1989; Mowbray, 1990; Susser *et al.* 1990).

Consumers and others, however, argue that empowerment in any context cannot be bestowed by those with greater power on those with less; it must be initiated from the bottom up by those who seek self-determination (Pinderhughes, 1983; Rappaport, 1985; Gruber & Trickett, 1987; Simon, 1987; Yeich & Levine, 1992). Consumers maintain their programmes truly empower people because consumer control and delivery of services facilitates this grassroots process of involvement absent in other organisations (Chamberlin, 1978; Zinman, 1987; Segal *et al.* 1993; Clay, 2005). They regard empowerment as the principle underlying consumer programme goals, processes and outcomes and thus it is central to the focus of this editorial – sharing of power within a structure that seeks to minimise hierarchal relationships. Empowerment through the organisational characteristics of a CRS is seen as enabling members to regain hope, self-esteem and self-confidence lost through stigmatisation as persons labelled 'mentally ill' (Leete, 1988; Kaufmann *et al.* 1989; Chamberlin, 1990). These goals are reflected in the principles and practice of the recovery model (Ralph *et al.* 2000). Thus, CRSs foster empowerment not merely by providing peer-based services but by allowing members to participate in organisational decision-making and governance (Segal *et al.* 1995).

Consumer control, while a necessary condition for a CRS, is not a sufficient condition to ensure that the organisation's empowerment ideology and its major contributions to client outcomes will be carried into practice. In a conversation with a director of a consumer-operated programme, it was divulged that '...sharing policy responsibilities with the mentally ill might be dangerous...' and was therefore not part of her organisational operations; 'providing services' was instead the focus. The mental health field has a long history, dating back to the subversion of moral treatment principles in early asylums, of compromising promising

psychosocial programming to accommodate either fiscal constraints or vocational ambitions. McLean (1995) offers a counterpoint to the great potential evidenced by CRSs. This qualitative study reports on the unfulfilled promise of a consumer-run drop-in centre embedded in a community mental health system and of the potentially disempowering effects of pursuing a combined services approach. McLean's findings associate the combined services approach with the abandonment of the key consumer service principle of participation in empowering decision-making and the sacrifice of goals to bureaucratic and funding pressures. A consumer operated service without its empowering approach may be no more than cheap care at best, not an agency within the conceptual and operational achievement of the mental health consumer movement's founders.

Having emphasised the importance of an empowering approach to CRS recovery-focused service, it must be acknowledged that making such programmes work is not a simple task. Empowering members is a strength but also a weakness of the CRS. The organisational functionality of more democratically oriented organisations is often challenging. The less hierarchical enterprises often appear to be more confusing and disorganised the more democratic their operations tend to get. This is also often accompanied by diffusion of responsibility and accountability – while people are empowered to take action within organisations when activities are enjoyable or self-serving, there may suddenly be fewer empowered people available to help as major organisational challenges arise. This can only be addressed by strong leadership that respects cooperative effort without exerting unidirectional control. Thus, CRS may seem a contradiction of mutual-support and wise leadership – in fact at its best it is a model of joint governance and needs to be evaluated as such.

Conclusion

As consumer-run agencies demonstrate their success in serving people with mental health challenges, they become recognised as a source of specialised knowledge; thus, they develop expert power (French & Raven, 1959). Providers of mental health services and other social services have invited consumers to assist them in making their services more responsive to the needs of their clientele. To the extent that consumer operated agency directors fail to appreciate the unique contribution of the empowering approach to their organisational successes and fail to protect it within their organisations, the consumer-run approach may ultimately join the ranks of previously promising but discredited psychosocial treatment efforts.

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Conflict of Interest

None.

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