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The Effectiveness of Consumer-Led Mental Health Services: An Integrative Review

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Abstract This study examined the evidence from controlled studies for the effectiveness of consumer-led mental health services. Following an extensive search of material published in English from 1980, predefined inclusion criteria were systematically applied to research articles that compared a consumer-led mental health service to a traditional mental health service. A total of 29 eligible studies were appraised; all of them were conducted in high-income countries. Overall consumer-led services reported equally positive outcomes for their clients as traditional services, particularly for practical outcomes such as employment or living arrangements, and in reducing hospitalizations and thus the cost of services. Involving consumers in service delivery appears to provide employment opportunities and be beneficial overall for the consumer-staff members and the service. Despite growing evidence of effectiveness, barriers such as underfunding continue to limit the use and evaluation of consumer-led services. Future studies need to adopt more uniform definitions and prioritize the inclusion of recovery oriented outcome measures.

Keywords Service users · Recovery · Empowerment · Consumer-led · Mental health services

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Introduction

Over the past two decades the recovery movement has sought to empower people with personal experience of mental illness to increase their activity in and control over mental health services (MHSs). Consumer involvement in mental health services, now established as public policy in many countries, has its origins in peer-support and self-help. Self-help groups arose in the 1970's, parallel to the discharge of large numbers of patients from psychiatric hospitals, and developed as consumers began to seek alternatives to traditional mental health services (Campbell 2005). New models of recovery were constructed, based on the needs of consumers as they defined them, and in 1989 the unique contribution consumers could make to mental health services was recognized at a national level in the United States (National Association of State Mental Health Program Directors 1989). The notion that consumers could participate and provide useful services to other people was based on several ideas, firstly that consumers might better identify or understand the issues associated with mental illness arising for their peers, and make unique contributions because of their personal experience; secondly that they might encourage participation of consumers in services, and finally that they could facilitate change in attitudes to mental illness. It was also realized that consumer involvement provided an opportunity for employment to people with a mental illness. The acceptance of consumer involvement expanded in the 1990's with the development of partnerships between consumer and traditional mental health services. However, internationally many government-run organizations that are responsible for providing services to people with severe mental illness are now grappling with how best to deliver services that are run by or involve consumers (Campbell 2005). Formal evaluation

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of consumer-led services has increased notably in the new millennium, with numerous studies using a wide range of study designs, interventions and outcomes.

For the purposes of this paper consumers are defined as individuals with mental illness who identify themselves as such and who have used MHSs. There are variations in how these individuals prefer to be addressed (Mueser et al. 1996), with literature from the United States favoring the term 'consumer', while that in the United Kingdom and Europe favoring 'service-user'.

The three main forms of consumer-led services in mental health services considered are autonomous consumer-run enterprises, consumer-led services within a traditional MHS (partnership), and consumer-participation within a traditional MHS. A consumer-led or consumer-run service can be defined as a service that is planned, administered, delivered or evaluated by a consumer group, based on needs defined by the consumer group. It is also referred to in the literature as a peer-run, user-led, or self-help service. They differ from consumer-participation in that consumers are the primary service providers. Potential services include case management, peer-support, peer-specialists (trained peer-supporters), inpatient hostels or crisis respite, advocacy, assessment/interview, education, research, auditing, funding or advisors in public policy. By identifying and appraising the international evidence, this integrative review seeks to determine if consumer-led mental health services or programs are effective, and seeks to inform consumers, providers or funders of MHSs, and those who determine policy and legislation.

Methods

Search Strategy

The literature was searched using the following primary databases: Medline, Embase, PsychINFO, Cinahl, the Cochrane Database of Systematic Reviews, and the Database of Abstracts of Review of Effectiveness, along with other electronic and library catalogue sources including the internet. Searches were limited to English language material published between 1980 and December 2008 inclusive. Key search terms included: consumer, service user, psychiatric survivor, consumer-led, consumer-run, user-led, user-run, patient led, patient managed, community, participation, social support, peer specialist, peer counseling, peer tutoring, self help, mental health services, mental health disorders and mental health programs. Terms related to substance abuse or dependence were excluded. Manual searching of journals, or contacting of authors for unpublished research were not undertaken in this review, with the exception of the Consumer-Operated Services Program (Campbell 2004). The rationale for this exception is that Campbell's work is the only large multi-site study to date investigating consumer-led services across eight distinct settings across the United States over 4 years (1998–2002).

Study Selection

Studies were independently selected for appraisal by two researchers, using a two-stage process. Initially, the titles and abstracts identified from the search strategy, including references cited in retrieved papers, were scanned and excluded where appropriate. The full text articles were then retrieved for the remaining studies, and included according to the criteria listed in Table 1.

Assessment of Level of Evidence

The strength of the evidence presented in the included studies was assessed and classified using a system developed by the National Health and Medical Research Council, Canberra, Australia (NHMRC 2000). This was determined by the study design, as an indicator of the degree to which bias had been eliminated by design. The six levels of evidence are: (I) Systematic review of all randomized controlled trials (RCT), (II) RCT primary research, (III-1) Pseudo-randomized controlled trials, (III-2) Comparative studies with concurrent controls and non-randomized allocation, (III-3) Comparative studies with historical control, two or more single arm studies, or interrupted time series without a parallel control group and (IV) Case series, either post-test or pre-test/post-test design.

Results

Over one thousand studies were identified by the search strategy. Twenty-nine articles were eligible for inclusion, consisting of two systematic reviews, 17 randomized controlled trials, three pseudo-randomized trials and seven comparative studies with alternate allocation. Twenty-one out of the 27 primary research papers were conducted in the US (78%), two from Canada (7%), two from Europe (7%), one from the UK (4%), and one from Australia (4%). It is worth noting there were no published studies found prior to 1990 which may suggest consumer-led mental health services or the recovery movement was still in early stage development in the 1980s. Even though where the studies were conducted was not the predefined inclusion criterion in the present review, all of the primary studies were conducted in high-income countries such as the UK and Australia. A high-income economy was defined by the World Bank as a country with a Gross National Income per

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Table 1 Inclusion criteria

Characteristic	Criteria
Date	1980 to December 2008 inclusive
Published	Peer reviewed journals[a]
Objective	To evaluate the effectiveness of a consumer-led mental health service
Study design	Systematic reviews, RCTs, Comparative studies with subject allocation
Comparison	Traditional mental health services
Sample size	Five or more people
Participants	Adults (aged 18 years or more) with an Axis I psychiatric disorder as classified by DSM-IV and/or ICD-10 or earlier versions of these, where less than half of the study population had a DSM IV substance abuse/dependence. Studies primarily concerned with participants with disabilities or other physical or neurological conditions were not included
Outcomes	Any outcome related to the consumers, the staff, or the service delivered
Language	English
Not included	Studies on forensic services, substance abuse or dependence services

[a] The multi-site study "Consumer-Operated Services Program" led by Campbell (2004) was identified through manual search and included in this review because of the significant contribution it made to the field of consumer-led services

capita of US$11,906 or more in 2008 (The World Bank 2010). Details of excluded studies or more comprehensive tables of included studies are available on request from the first author.

Included studies were classified according to their level of evidence, and summarized in Tables 2 and 3 indicating: consumer involvement, study design, interventions and type of MHS provided, outcomes measured, and main conclusions, including differences between consumer-led and traditional organizations. Other than cost outcomes, only statistically significant differences were reported. Consumer involvement was categorized by the service provided and according to whether the intervention was an entirely consumer-run organization, a consumer-led service, or consumer participation initiative. Numerous outcomes were used to measure the effectiveness of consumer-led MHSs, relating to the client, consumer-staff, or the service itself. These are summarized in Table 4 using categories similar to the standardized National Outcomes Measures previously developed by the Substance Abuse and Mental Health Services Administration (2005).

Discussion

Two Previous Reviews

A systematic review produced by the University of Leeds in 2002 (Simpson and House 2002) also considered the evidence involving consumers in the delivery and evaluation of mental health. This was based on research published between 1966 and 2001, and included randomized controlled trials and comparative studies. They found that involving consumers as employees of MHSs led to clients having greater satisfaction with their personal circumstances and less hospitalization. The authors concluded that MHS consumers can be involved as employees, trainers, or researchers without detrimental effect, and that involving consumers with severe mental disorders is feasible. Another systematic review with identical review title, carried out by Davidson and colleagues (1999, 2005) found that naturally occurring mutual support groups may improve symptoms, promote wider social networks and enhance quality of life. However, as the review included mostly uncontrolled studies, evidence on effectiveness was inconclusive.

Trends on Effectiveness and Other Observations of Consumers-Led Services

Consumer Involvement

Eighteen of the 27 primary research papers studied consumers participating within a traditional mental health service as peer supporters/specialists, health care assistants, case managers, advocates, educators or interviewers. Eight were of entirely consumer-run programs, including a crisis hostel, self-help programs, drop-in centers, peer support, advocacy, case managers or educators. Only one study reported a consumer-led service as a partnership within a traditional MHS (Forchuk et al. 2005). This may indicate that a partnership approach is not clearly delineated as such in published reports. One of the concerns brought up in the literature is 'tokenism'—that consumers will be involved only at a superficial level without any real power to make decisions about service delivery. This was difficult to determine from the papers on consumer-participation, so future studies should seek to explicitly report the extent of control consumers exert over decision making in their respective services, to examine who and who do not benefit

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Table 2 Summary of randomized controlled studies comparing the effectiveness of consumer-run and traditional mental health services (level of evidence II, 17 studies)

Study	Consumer involvement	Methods	Between-group differences
Campbell (2004)	*Entirely* consumer-run organizations	*Design:* Multi-centre RCT (n = 1,827) *Interventions:* 1. Both traditional services and eight consumer-operated service programs that emphasized self-help as their operational approach, including four drop-in centers, two mutual support programs, and two educational/ advocacy programs 2. Traditional service	1. Both experimental and control groups showed improved well-being over time 2. Participants assigned to both consumer-run and traditional services showed greater improvement in well-being over the course of study than participants assigned only to traditional services
Castelein et al. (2008)	*Entirely* consumer-run program with minimum input from professionals	*Design:* Multi-center RCT (n = 106) *Interventions:* Peer support program 1. 8-Month study of peer support with minimal involvement from professional 2. The key point was to provide peer-to-peer interaction; participants decided on the topic	1. Positive effect on social network, social support and quality of life (QoL) 2. Group attendance or intervention adherence was an important condition for its effects
Clark et al. (1999)	Interviewers participating within a traditional MHS	*Design:* Dual-centre, RCT (n = 120) *Setting:* Two centers for Addiction and Mental Health *Intervention*: Interview by: 1. Staff member 2. Client	Clients interviewed by clients: 1. Reported being ill for a longer period of time 2. Gave more negative responses about services received 3. Had no difference in overall satisfaction with services
Clarke et al. (2000)	Individual Case Managers within an entirely consumer-run MHS	*Design:* Single centre, RCT (n = 163) *Interventions:* Providers of Assertive Community Treatment (ACT) with: 1. Consumer case managers 2. Non-consumer case managers	Clients with consumer case managers: 1. Had less hospitalizations and emergency room visits 2. Had no differences in time to first homelessness, arrest or ER visit
Cook et al. (1995)	Individual Educators participating in a traditional MHS	*Design:* Single-program RCT (n = 57) *Interventions:* Training of mental health professionals on delivering Assertive Community Treatment from: 1. Consumer trainer 2. Non-consumer trainer	Health professionals trained by the consumer trainer: 1. Had more positive attitudes toward people with mental illness 2. Felt more positively about consumers as service providers and trainers 3. Expressed more non-stigmatizing attitudes

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Table 2 continued

Study	Consumer involvement	Methods	Between-group differences
Craig et al. (2004)	Individual Health Care Assistants, participating in a traditional MHS	*Design:* Single-center RCT ($n = 45$) *Interventions:* An assertive outreach mental health service involving: 1. Case management plus a consumer-employee as health care assistant 2. Standard case management (CM)	Clients allocated to the consumer assistant: *Staff perspectives:* 1. Had lower rates of non-attendance to appointments 2. Had higher levels of participation in structured social activity 4. Had improvements in communication and social contacts 5. Had fewer unmet practical needs (daytime activity, company, finances, transport, access to benefits) 6. Had no difference in self-care, turbulence or responsibility 7. Had no differences in number or length of hospitalization *Client perspectives:* 1. Had fewer unmet practical needs (same as above) 2. Had no differences in social networks 3. Had no differences in satisfaction with services
Davidson et al. (2004)	Individual Peer Supporters participating in traditional MHSs	*Design:* Single-program multi-site RCT ($n = 260$) *Interventions:* 1. Peer support from a consumer-partner with a similar history of psychiatric disability 2. Social support from a partner without personal experience of psychiatric disability 3. No peer or social support provided	1. Participants assigned peer support improved in psychiatric symptoms, social functioning, self-esteem well-being and satisfaction when they did not regularly meet with their consumer-partners 2. Participants assigned social support improved in psychiatric symptoms, social functioning, self-esteem well-being and satisfaction when they did meet regularly with their partners 3. Depressive symptoms did not improve in any of the three groups (see interventions design)

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Table 2 continued

Study	Consumer involvement	Methods	Between-group differences
Dumont and Jones (2002)	*Entirely* consumer-run organization	*Design:* Single-center RCT ($n = 265$) *Interventions:* 1. Access to a consumer-run crisis hostel and peer support as well as traditional hospital-based services 2. Access to hospital-based services only	Those with access to the hostel had: 1. Significantly less hospital admissions 2. Shorter duration of stays in hospitals 3. Greater levels of satisfaction with services The cost per patient for crisis services was reduced by almost a third when they were given access to the hostel (US$3,187 vs. US$2,018)
Forchuk et al. (2005)	Individual Peer Supporters, a consumer-led service as a partnership within a traditional MHS	*Design:* Single-program cluster randomized study ($n = 26$) 1. Transitional discharge model (TDM) with in-patient staff continuing care plus peer support 2. Standard model of discharge care	Discharged patients participating in TDM: 1. Had no difference in global QoL 2. Had a greater improvement in social relations 3. Consumed $4,400 CDN less hospital and emergency room services per person
Greenfield et al. (2008)	*Entirely* consumer-run, crisis residential program	*Design:* Multi-center RCT ($n = 393$) *Interventions:* Solely operated by mental health consumers or received minimal input from professional staff 1. Experimental condition- consumer-run, crisis residential program, emphasizing client decision, involvement in recovery and also the importance of experiential learning 2. Usual care condition- locked, inpatient psychiatric facility, run by medically trained professional staff	1. Greater mean improvement for psychiatric symptoms and strengths, and treatment satisfaction for the experimental group 2. Consumer-run, crisis residential services are viable, cost-effective alternatives to more restrictive, traditional, acute inpatient services
Kaufmann (1995)	Peer Support groups, participating in a traditional MHS	*Design:* Single-center RCT ($n = 161$) *Interventions:* Employment 1. Self Help Employment Center (SHEC) providing peer support groups and a consumer-led self help program 2. Community vocational services	Participants attending the SHEC: 1. Had a higher vocational status 2. Took less time to find a job 3. Had no difference in average hourly wage 4. Did not remain in their jobs for as long

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Table 2 continued

Study	Consumer involvement	Methods	Between-group differences
Klein et al. (1998)	Individual Peer Specialists participating in a traditional MHS	*Design:* Single-centre, single-program RCT ($n = 61$) *Interventions:* Peer social support program involving: 1. Intensive case management (ICM) coupled with an individual peer supporter (Friends Connection) 2. Intensive case management only	Clients who received ICM plus a peer supporter: 1. Had far less crisis events and inpatient days 2. Improved in social functioning 3. Improved in living arrangements, income and health 4. Decreased substance abuse [control group increased] 5. Were engaged in fewer community activities 6. Had no difference in social interaction 7. Had no difference in interaction with friends and family Cost savings due to the reduction in inpatient days was estimated at US$22,000/client for 6 months
O'Donnell et al. (1999)	Advocates participating in a traditional MHS	*Design:* Single-centre RCT ($n = 119$) *Interventions:* 1. Client-focused CM plus consumer advocacy 2. Client-focused CM 3. Standard case management	Clients who received client-focused CM plus consumer advocacy: 1. Had a lower family burden of care 2. Had no differences in functioning, disability, QoL, satisfaction with services, burden of care or number of days in hospital Case manager advocates had higher levels of satisfaction working with clients
Paulson et al. (1999)	Individual Case Managers within an entirely consumer-run MHS	*Design:* Single centre, RCT ($n = 5$) *Interventions:* Providers of Assertive Community Treatment (ACT) with: 1. Consumer case managers 2. Non-consumer CMs	1. There were few differences in the pattern of either administrative or direct service tasks performed by the two teams. However, the consumer team emphasized "being there" with the client while the non-consumer team was more concerned with accomplishing tasks 2. The consumer team spent twice as much time in supervision and regularly discussed the impact of job stress on their psychological well-being

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Table 2 continued

Study	Consumer involvement	Methods	Between-group differences
Sells et al. (2006)	Individual Case Managers participating in a traditional MHS	*Design:* Single-program, single-center Single-program RCT ($n = 137$) *Interventions:* Assertive Case Management by: 1. Peer providers 2. Regular providers	Clients with peer case managers: 1. Reported feeling more liked, understood and accepted by their providers after 6 months of treatment, but these effects disappeared at 12 months 2. Showed increasing contacts with providers over 6 months, (client with case managers showed decreasing contact)
Solomon and Draine (1995a, b, 1996)	Individual Case Managers, as a consumer-run service	*Design:* Single-centre RCT ($n = 96$) *Interventions:* Intensive case management with teams of: 1. Consumer case managers 2. Non-consumer CMs	Consumer managers: 1. Provided more services face-to-face with the client or at another provider agency, rather than in their office or by collateral contact with family or friends 2. Were concerned about acceptance by other mental health professionals, maintained less collateral contact with other professionals, and did not show any greater signs of stress, diminished self esteem, or burnout 3. Had no difference in the number of service contacts or total units of service Clients served by consumer case managers: 1. Had less satisfaction with mental health treatment 2. Had less contact with family members 3. Had no differences in symptoms, level of functioning, hospitalizations, attitudes to medications, satisfaction with treatment, and QoL
Wood and Wahl (2006)	Individual Educators, as an entirely consumer-run program	*Design:* Single-program RCT ($n = 114$) *Interventions:* 1. In Our Own Voice (IOOV) a consumer-led anti-stigma program to educate consumers, mental health professionals, students, and police officers 2. Presentation on careers in psychology	Students who attended IOOV had greater changes in knowledge and attitudes about mental illness

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Table 3 Summary of comparative studies comparing the effectiveness of consumer-run and traditional mental health services (level of evidence III-1 and 2, 10 studies; no III-3 articles were found)

Study	Consumer involvement	Methods	Between-group differences
Felton et al. (1995)	Individual Peer Specialists participating within a traditional MHS	*Design:* Single center, longitudinal study *Evidence level:* III-1 ($n = 104$) *Interventions:* Intensive case management program with: 1. Case Managers plus peer specialists 2. CMs plus non-consumer assistants 3. CMs only	Clients receiving ICM plus peer specialists: 1. Had greater gains in QoL and less major life problems experienced 2. Had greater satisfaction with services and personal finances 3. Had no difference in self-image, outlook, engagement in program or community tenure
Polowczyk et al. (1993)	Interviewers participating within a traditional MHS	*Design:* Single center, comparative study ($n = 530$) *Evidence Level:* III-1 *Interventions:* Survey, as part of assessment of patients, by: 1. Clinic patients/consumers 2. Clinic staff	Respondents surveyed by a consumer reported lower satisfaction with the outpatient services than patients surveyed by a staff member (90% compared to 95%; respondents did not know if the surveyor was a consumer or staff)
Powell et al. (2000)	Individual Peer Specialists plus a self-help group as part of a consumer-run organization	*Design:* Multi-center, multi-program longitudinal study ($n = 226$) *Evidence level*: III-1 *Interventions:* 1. Stabilized peer supporter accompanying patient to a self-help group 2. Usual professional care only	Patients accompanied to a self-help group by a peer specialist were more likely to attend self-help groups than patients without this support (56% compared to 15%) *Limit:* The control group did not have any extra support, so cannot say it was consumer-involvement that was helping. Also, the outcome presumes that attending the self-help group is beneficial
Burti et al. (2005)	*Entirely* consumer-run program	*Design:* Single- community psychiatric services, 2-year study ($n = 88$) *Evidence level:* III-2 *Interventions:* 1. Consumer run self-help group 2. Regular community mental health services	Clients who attended the consumer run self-help group: 1. Decreased their number of admissions during the study period, duration of stay in hospital and higher level of service satisfaction; while non-self-group members identified higher number of unmet needs 2. Had no difference in symptoms and level of disability compared with non-self-help group members
Chinman et al. (2000)	Individual Case Managers participating within a traditional MHS	*Design:* Single-program, multi-center, longitudinal study ($n = 2{,}935$) *Evidence level:* III-2 *Interventions:* An outreach program with: 1. Consumer Case Managers 2. Non-consumer CMs	There were almost no differences in either baseline characteristics, outcomes, or relationship variables between the two groups There were no differences in the presence and strength of the Case Manager relationship
Chinman et al. (2001)	*Entirely* consumer-run program	*Design:* Single-center, longitudinal study ($n = 158$) *Evidence level:* III-2 *Interventions:* 1. Outpatient services plus the consumer-run Welcome Basket Program (WBP) 2. Outpatient services	1. Clients who received outpatient services plus the consumer-run Welcome Basket Program over the first year of operation had a 50% reduction in re-hospitalizations 2. Comparison of *matched sample of people* between two time-points showed there were no differences in the number of re-admissions to hospital or the number of inpatient days

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Table 3 continued

Study	Consumer involvement	Methods	Between-group differences
Kane and Blank (2004)	Individual Peer Specialists participating within a traditional MHS	*Design:* Multi-center, single-program, longitudinal study ($n = 59$) *Evidence level:* III-2 *Interventions:* Assertive Community Treatment: 1. Stabilized peer providers (trained by psychiatric nurses) 2. Nurse care only	Consumers with stabilized peer providers had: 1. Less physical symptoms 2. Greater improvement in psychiatric symptoms 3. Better community adjustment 4. Greater satisfaction with services There were no differences in: 1. Disability 2. Dyskinesia (abnormal movements) experienced 3. Health promoting lifestyle
Nelson et al. (2006a, b), Ochocka et al. (2006)	*Entirely* consumer-run, peer support program	*Design:* Multi-program longitudinal study *Evidence level:*III-2 ($n = 118$) *Interventions:* 1. Four entirely consumer-run organizations 2. None	Participants of consumer-run organizations had: 1. Small increase in QoL, rather than decrease in QoL 2. Less days spent in psychiatric hospitalization 3. Less use of emergency services 4. Greater proportion maintained employment or education From the interviews participants of consumer-run organizations had: 1. more stable mental health 2. Enhance social support 3. Sustained work 4. Stable income 5. Greater participation in education/training
Uttaro et al. (2004)	Survey administrators participating within a traditional MHS	*Design:* Single-center longitudinal study *Evidence level:* III-2 ($n = 511$) *Interventions:* Survey administration by: 1. Consumers 2. Unit staff 3. Quality management staff	Unit staff elicited higher responses in satisfaction with services from inpatients than consumers or quality management staff
Young et al. (2005)	*Entirely* consumer-run program	*Design:* Single-program, multi-center, longitudinal study ($n = 269$) *Evidence level*: III-2 *Interventions:* 1. Consumer-run program: Staff Supporting Skills for Self-Help 2. Traditional MHS	The clinicians working in the consumer-run program improved in: 1. Teamwork 2. Education about care 3. Overall competency 4. Recovery orientation

from such user-led interventions. It is interesting to note that all studies on entirely consumer-run services were published recently, after the year 2000.

Consumers as Staff Members

O'Donnell et al. (1999) found that consumer advocates had greater job-satisfaction than non-consumer advocates, and Solomon and Draine (1996) found that consumer case managers did not show any greater signs of stress, diminished self-esteem or burnout than traditional staff, although they were concerned about their acceptance by other mental health professionals. Paulson et al. (1999), however, reported that consumer case managers spent more time in supervision than their non-consumer colleagues and regularly discussed the impact of job stress on their psychological well-being. The authors stated that "Consumers may also have limitations as service providers, such as

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Table 4 Outcomes used to measure the effectiveness of consumer-led services

Type of Client satisfactions		Client satisfaction or perception of the consumer-led or traditional service
Client recovery	Emotional and mental wellbeing	Quality of life, meaning of life, self-esteem, self-direction, self-image, outlook, empowerment, life-satisfaction, hope
	Symptoms	Psychiatric, depressive, physical, arrest, disability, major life problems experienced, number of crisis events, substance use
	Social	Social functioning, social contacts, social networks, social relations, social support, social interaction, social inclusion, community integration, relationship with service staff, participation in structured social activities
Meeting clients' practical needs	Employment	Employment, education/vocational training
	Housing	Housing, days of homelessness
	Financial	Level of income, reliance on financial support, access to benefits
	Access	Engagement in program, number of service meetings attended
	Other	Transport, level of functioning, attitudes to use of medication, involvement in treatment decisions, assistance obtaining meals and groceries, healthy lifestyle
Consumer as staff		Psychological well-being, engagement in job, competency, care processes, formation of mutual support, coping with job stress, job satisfaction, self-esteem
Perceptions of others		Improved attitudes or knowledge about recovery or people with mental illness
Service outcomes	Quality	Type of service provision, number of service contacts made, frequency of hospitalizing patients involuntarily or voluntarily, number of emergency dispatches made
	Utilization	Number, nature or duration of hospitalization/s, time until first hospitalization, use of emergency hospital care, use of crisis services
	Cost	Cost saved per client based on hospitalization rates

increased vulnerability to the stressful nature of MHS delivery in general, and case management in particular; difficulties in maintaining appropriate boundaries and stigmatization by other mental health professionals" (p. 253). They mentioned that consumers involved in service provision might require special supports to prevent burn-out or relapse. Chinman et al. (2000), added some of the potential difficulties that consumer-led services may encounter, including "role confusion, discrimination from co-workers, feelings of being a "second class" employee, and feelings of being under compensated for their work" (p. 451). On the other hand, they also pointed out the potential for consumer involvement to create meaningful employment for people who have a mental illness.

Satisfaction with Services

There is some debate about whether satisfaction with services should be used as a mental health outcome measure (Gordon et al. 2004). Consumers have argued in favor of its use asserting that consumers have a right to services with which they are happy and satisfaction is imperative to achieving full involvement of consumers (Graham et al. 2001). Nine studies measured clients' satisfaction with consumer-led services compared to usual mental health services. Six of these studies reported clients to have greater satisfaction with the consumer-led intervention (Burti et al. 2005; Davidson et al. 2004; Dumont and Jones 2002; Felton et al. 1995; Greenfield et al. 2008; Kane and Blank 2004), while two found no differences (Craig et al. 2004; O'Donnell et al. 1999). One study (Solomon and Draine 1995b) reported lower satisfaction with services in the consumer-led intervention. Sells and colleagues (Sells et al. 2006) found that clients of the consumer-led intervention had greater satisfaction with services earlier in the intervention process, with traditional services catching up after 1 year, which might provide one possible explanation for the heterogeneity in results for this outcome. Another explanation is that studies often reported very high levels of satisfaction with services for both consumer and non-consumer groups, although some studies reported a small but statistical significant difference between the groups.

Clients' Recovery- Emotional, Social, Symptomatic and Practical Outcomes

Twelve studies measured a variety of outcomes relating to client recovery (Burti et al. 2005; Castelein et al. 2008; Chinman et al. 2000; Craig et al. 2004; Davidson et al. 2004; Felton et al. 1995; Greenfield et al. 2008; Kane and Blank 2004; Klein et al. 1998; Nelson et al. 2006b; O'Donnell et al. 1999; Ochocka et al. 2006). The majority of results showed either no differences, or greater recovery for those in the consumer-led interventions compared to traditional services, across all three categories of emotional, social or symptomatic recovery. Other recent studies

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published in 2008 (Castelein et al. 2008; Greenfield et al. 2008) found similar results in that user-led self-help programs had a positive effect on self-reported and clinician-rated psychopathology and other positive measures (e.g., quality of life, social network, self-efficacy and self-esteem). Three studies reported negative findings. Davidson et al. (2004) found that clients improved in all three categories if they met regularly with a person from the general community, but worsened if they met regularly with a consumer peer supporter. Klein et al. (1998) found that clients given individual peer support were engaged in fewer community activities than those without the peer support. However, sample size for this study was very limited with only 10 participants in the consumer group. Solomon and Draine (1995b) found that clients with consumer case managers had less contact with their families than those with non-consumer case managers. To sum up, in most studies, clients who used consumer-run or consumer led services consistently had greater improvements in practical outcomes, including employment (Kaufmann 1995), finances (Craig et al. 2004; Felton et al. 1995; Klein et al. 1998), education (Nelson et al. 2006b; Ochocka et al. 2006), living arrangements (Klein et al. 1998), and transport (Craig et al. 2004). There is some evidence that involvement with consumer-staff may restrict the evolution of natural community and family supports (e.g., Davidson et al. 2004; Klein et al. 1998).

Categories of Outcomes

Given the heterogeneity of studies in this field and the lack of power (due to sample size) to detect an effect, standardization of outcomes and routine reporting of effect sizes from individual studies will be crucial for comparisons of different models of service delivery. This approach may also allow for meta-analytic techniques to be utilized for pooling the results of future studies. Additional outcomes reported that are missing from the National Outcomes Measures were emotional and mental recovery from the clients' perspective, spiritual wellbeing, level of income, and other practical/living outcomes such as the need for assistance obtaining meals and groceries. Although it is necessary to measure outcomes related to the provision and funding of services, outcomes that are meaningful to consumers and their quality of life must also be included (Gordon 2009; Gordon et al. 2004). Internationally a number of different instruments are being developed and validated for use across countries. For example, in Australia, Anderson et al. (2006) developed the Stages of Recovery Instrument (STORI) to measure recovery as a concept described by consumers. Researchers have highlighted the critical importance of involving consumers at every stage of the development of relevant outcome measures (Allott et al. 2006; Gordon 2006; Gordon et al. 2004).

Overall Service Outcomes

The validity of data collection methods by consumer interviewers compared to staff members within a traditional mental health service was evaluated in three studies, all of which found that clients interviewed by a consumer were more likely to reveal negative responses about satisfaction with services (Clark et al. 1999; Polowczyk et al. 1993; Uttaro et al. 2004).

In terms of the quality of service, Paulson et al. (1999) found that the consumer team emphasized 'being there' with the client while the non-consumer team was more concerned with accomplishing tasks. Solomon and Draine (1996) reported a similar finding in that consumer case managers were more likely to provide face-to-face services with the client. However, they also found there was no overall difference in the number of service contacts made. Young et al. (2005) found that a consumer-run program had increased competencies on some scales, but not on others when compared to a traditional MHS.

The majority of studies found a reduction in hospitalizations (e.g., Chinman et al. 2001; Clarke et al. 2000; Dumont and Jones 2002; Forchuk et al. 2005; Klein et al. 1998; Nelson et al. 2006a), although one study found no differences (O'Donnell et al. 1999). Three of these studies evaluated cost effectiveness based on hospitalization, finding cost savings per patient [US$1,169/12 months (Dumont and Jones 2002), US$4,400/12 months (Forchuk et al. 2005), US$22,000/6 months (Klein et al. 1998)] for the consumer-led service. The latter of these studies (Klein et al. 1998) was the least reliable due to the small sample size.

Conclusions

To make a strong case for their place in the array of services offered by the mental health sector, consumer-led services are required to demonstrate at least equivalent effectiveness to a traditional service in regard to outcomes for clients. Overall, consumer-led services seemed to report equally positive outcomes for their clients as traditional services, particularly for practical outcomes such as employment, income, education or living arrangements, and in reducing hospitalizations and the cost of services. Results were varied for client satisfaction and recovery, and some negative findings were reported. Consumers as interviewers may increase the validity of reporting on satisfaction with services. Involving consumers in services can provide employment opportunities and is both

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beneficial for the consumer-staff members and the service. However many barriers to full inclusion still exist (e.g., fair pay scale for consumer working in mental health field, discrimination within mental health system), so consumer-staff may need extra support. It is imperative that researchers continue to focus on the standardization of outcomes and definitions, and that consumers are involved as an integral part of the research process so that outcomes are meaningful to them. Further research is also needed to evaluate consumer-led services participating within traditional MHSs and to compare the different models of service delivery and the array of consumer-staff roles.

Limitations

This review used a structured approach to review the literature and the scope was confined to an examination of the effectiveness of the service or program. Although this review does not consider the acceptability of the service to users or funders, or any ethical, economic or legal considerations associated with consumer-led services, these are important issues worthy of further study. The majority of the reviewed articles were written by health professionals, with or without input from consumers, which might have influenced the studies design and the choice of outcomes measured. The studies included in the present review were conducted in high-income, English speaking countries therefore the findings may not be generalizable to countries where low incomes or different cultural influences or approaches to mental health predominate. Descriptive or qualitative studies were not included as they are not designed to quantify the effectiveness of services. However, qualitative research is useful in providing a rich description of how consumer-led services are delivered, the unique experience and perceptions of service providers and consumers, and the specific context of individual programs.

Future Research

Research in the future needs to incorporate standardized outcomes, including a core set of primary outcomes which are consistently reported by all investigators. Indeed some outcomes consumers identified as important, for example whether or not they have achieved their own goals, leisure time, access to legal aid, and family burden (Rapp and Goscha 2006), were missing altogether from the studies we reviewed. Another important line of investigation is to examine how the intervention process (e.g., level of self-disclosure, or giving help) relates to outcomes. Most studies did not measure long term effects, particularly following the conclusion of a program, and they rarely addressed concerns raised in the literature about issues such as confidentiality, participants' level of attendance during the course of study, suitability of suggestions made by consumer-staff (Crawford and Rutter 2004), and the level of evidence-based practice (Summers 2003). These barriers need to be addressed to allow for consumer involvement in services, and some form of standard training may need to be implemented.

There were a limited number of studies on consumer-led services as partnerships with traditional services, and no studies that measured outcomes based on the level of participation of the consumers. There were no studies, for example, that looked at service reform with consumers in a position of funding or policy planning of a traditional MHS. Goldstrom and associates (2006) also found that traditional and consumer-led services were really still two distinct entities. To date there is no published study to compare roles of consumers, for example consumers as case managers versus peer-specialists. For research to advance we also need to agree on uniform definitions of consumer-led services, and we need to adopt a partnership approach to conducting the research. Both qualitative and quantitative methodology can be used, but both must be implemented robustly as well as consumer driven, that is instigated, organized and reported by consumers. Well-designed, longitudinal effectiveness studies would be useful for addressing the lack of data on longer-term outcomes.

Chen (1990) suggests that evaluators should first address whether programs are serving their targeted beneficiaries, with service delivery activities and programs as intended, and meeting their specified objectives. Once this is assured, experimental designs for outcome evaluation may be considered, but not before. Otherwise it cannot be known whether unsuccessful outcomes reflect failure of the specified model or failure to implement the model as specified.We recommend that due to the high drop-out rates in primary research of this topic, both an 'intention to treat' and 'as-treated' analyses need to be done. Also, although tricky, where feasible the participants should be blind to which service they are receiving, as was done in the study by Forchuk and colleagues (2005).

Lastly, consumers should determine the style of consumer-led services to be developed. Health professionals, researchers and policy planners can advocate for the continued support of existing consumer providers and can assist in the development of new services through the provision of material resources, ongoing support and workforce training. Ultimately, as Mowbray and Tan (1993) suggest, it is the mental health consumers themselves who will create the services and make them work.

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