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

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7 **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.

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

**Introduction** 30

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

67 For the purposes of this paper consumers are defined as  
68 individuals with mental illness who identify themselves as  
69 such and who have used MHSs. There are variations in  
70 how these individuals prefer to be addressed (Mueser et al.  
71 1996), with literature from the United States favoring the  
72 term 'consumer', while that in the United Kingdom and  
73 Europe favoring 'service-user'.

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

## 94 Methods

### 95 Search Strategy

96 The literature was searched using the following primary  
97 databases: Medline, Embase, PsychINFO, Cinahl, the  
98 Cochrane Database of Systematic Reviews, and the Data-  
99 base of Abstracts of Review of Effectiveness, along with  
100 other electronic and library catalogue sources including the  
101 internet. Searches were limited to English language mate-  
102 rial published between 1980 and December 2008 inclusive.  
103 Key search terms included: consumer, service user, psy-  
104 chiatric survivor, consumer-led, consumer-run, user-led,  
105 user-run, patient led, patient managed, community, par-  
106 ticipation, social support, peer specialist, peer counseling,  
107 peer tutoring, self help, mental health services, mental  
108 health disorders and mental health programs. Terms related  
109 to substance abuse or dependence were excluded. Manual  
110 searching of journals, or contacting of authors for unpub-  
111 lished research were not undertaken in this review, with the  
112 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

117  
118 Studies were independently selected for appraisal by two  
119 researchers, using a two-stage process. Initially, the titles  
120 and abstracts identified from the search strategy, including  
121 references cited in retrieved papers, were scanned and  
122 excluded where appropriate. The full text articles were then  
123 retrieved for the remaining studies, and included according  
124 to the criteria listed in Table 1.

### Assessment of Level of Evidence

125  
126 The strength of the evidence presented in the included  
127 studies was assessed and classified using a system devel-  
128 oped by the National Health and Medical Research  
129 Council, Canberra, Australia (NHMRC 2000). This was  
130 determined by the study design, as an indicator of the  
131 degree to which bias had been eliminated by design. The  
132 six levels of evidence are: (I) Systematic review of all  
133 randomized controlled trials (RCT), (II) RCT primary  
134 research, (III-1) Pseudo-randomized controlled trials,  
135 (III-2) Comparative studies with concurrent controls and  
136 non-randomized allocation, (III-3) Comparative studies  
137 with historical control, two or more single arm studies, or  
138 interrupted time series without a parallel control group  
139 and (IV) Case series, either post-test or pre-test/post-test  
140 design.

## Results

141  
142 Over one thousand studies were identified by the search  
143 strategy. Twenty-nine articles were eligible for inclusion,  
144 consisting of two systematic reviews, 17 randomized con-  
145 trolled trials, three pseudo-randomized trials and seven  
146 comparative studies with alternate allocation. Twenty-one  
147 out of the 27 primary research papers were conducted in  
148 the US (78%), two from Canada (7%), two from Europe  
149 (7%), one from the UK (4%), and one from Australia (4%).  
150 It is worth noting there were no published studies found  
151 prior to 1990 which may suggest consumer-led mental  
152 health services or the recovery movement was still in early  
153 stage development in the 1980s. Even though where the  
154 studies were conducted was not the predefined inclusion  
155 criterion in the present review, all of the primary studies  
156 were conducted in high-income countries such as the UK  
157 and Australia. A high-income economy was defined by the  
158 World Bank as a country with a Gross National Income per

**Table 1** Inclusion criteria

Characteristic	Criteria
Date	1980 to December 2008 inclusive
Published	Peer reviewed journals <sup>a</sup>
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

<sup>a</sup> 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

159 capita of US\$11,906 or more in 2008 (The World Bank  
160 2010). Details of excluded studies or more comprehensive  
161 tables of included studies are available on request from the  
162 first author.

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

## 180 Discussion

### 181 Two Previous Reviews

182 A systematic review produced by the University of Leeds  
183 in 2002 (Simpson and House 2002) also considered the  
184 evidence involving consumers in the delivery and evalua-  
185 tion of mental health. This was based on research pub-  
186 lished between 1966 and 2001, and included randomized  
187 controlled trials and comparative studies. They found  
188 that involving consumers as employees of MHSs led to  
189 clients having greater satisfaction with their personal

190 circumstances and less hospitalization. The authors con-  
191 cluded that MHS consumers can be involved as employees,  
192 trainers, or researchers without detrimental effect, and that  
193 involving consumers with severe mental disorders is fea-  
194 sible. Another systematic review with identical review title,  
195 carried out by Davidson and colleagues (1999, 2005) found  
196 that naturally occurring mutual support groups may  
197 improve symptoms, promote wider social networks and  
198 enhance quality of life. However, as the review included  
199 mostly uncontrolled studies, evidence on effectiveness was  
200 inconclusive.

### 201 Trends on Effectiveness and Other Observations 202 of Consumers-Led Services

#### 203 *Consumer Involvement*

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

**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	<p><i>Design:</i> Multi-centre RCT (<math>n = 1,827</math>)</p> <p><i>Interventions:</i></p> <ol style="list-style-type: none"> <li>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</li> <li>Traditional service</li> </ol>	<ol style="list-style-type: none"> <li>Both experimental and control groups showed improved well-being over time</li> <li>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</li> </ol>
Castelein et al. (2008)	Entirely consumer-run program with minimum input from professionals	<p><i>Design:</i> Multi-center RCT (<math>n = 106</math>)</p> <p><i>Interventions:</i> Peer support program</p> <ol style="list-style-type: none"> <li>8-Month study of peer support with minimal involvement from professional</li> <li>The key point was to provide peer-to-peer interaction; participants decided on the topic</li> </ol>	<ol style="list-style-type: none"> <li>Positive effect on social network, social support and quality of life (QoL)</li> <li>Group attendance or intervention adherence was an important condition for its effects</li> </ol>
Clark et al. (1999)	Interviewers participating within a traditional MHS	<p><i>Design:</i> Dual-centre, RCT (<math>n = 120</math>)</p> <p><i>Setting:</i> Two centers for Addiction and Mental Health</p> <p><i>Intervention:</i> Interview by:</p> <ol style="list-style-type: none"> <li>Staff member</li> <li>Client</li> </ol>	<p>Clients interviewed by clients:</p> <ol style="list-style-type: none"> <li>Reported being ill for a longer period of time</li> <li>Gave more negative responses about services received</li> <li>Had no difference in overall satisfaction with services</li> </ol>
Clarke et al. (2000)	Individual Case Managers within an entirely consumer-run MHS	<p><i>Design:</i> Single centre, RCT (<math>n = 163</math>)</p> <p><i>Interventions:</i> Providers of Assertive Community Treatment (ACT) with:</p> <ol style="list-style-type: none"> <li>Consumer case managers</li> <li>Non-consumer case managers</li> </ol>	<p>Clients with consumer case managers:</p> <ol style="list-style-type: none"> <li>Had less hospitalizations and emergency room visits</li> <li>Had no differences in time to first homelessness, arrest or ER visit</li> </ol>
Cook et al. (1995)	Individual Educators participating in a traditional MHS	<p><i>Design:</i> Single-program RCT (<math>n = 57</math>)</p> <p><i>Interventions:</i> Training of mental health professionals on delivering Assertive Community Treatment from:</p> <ol style="list-style-type: none"> <li>Consumer trainer</li> <li>Non-consumer trainer</li> </ol>	<p>Health professionals trained by the consumer trainer:</p> <ol style="list-style-type: none"> <li>Had more positive attitudes toward people with mental illness</li> <li>Felt more positively about consumers as service providers and trainers</li> <li>Expressed more non-stigmatizing attitudes</li> </ol>

Table 2 continued

Study	Consumer involvement	Methods	Between-group differences
Craig et al. (2004)	Individual Health Care Assistants, participating in a traditional MHS	<p><i>Design:</i> Single-center RCT (<math>n = 45</math>)</p> <p><i>Interventions:</i> An assertive outreach mental health service involving:</p> <ol style="list-style-type: none"> <li>1. Case management plus a consumer-employee as health care assistant</li> <li>2. Standard case management (CM)</li> </ol>	<p>Clients allocated to the consumer assistant:</p> <p><i>Staff perspectives:</i></p> <ol style="list-style-type: none"> <li>1. Had lower rates of non-attendance to appointments</li> <li>2. Had higher levels of participation in structured social activity</li> <li>4. Had improvements in communication and social contacts</li> <li>5. Had fewer unmet practical needs (daytime activity, company, finances, transport, access to benefits)</li> <li>6. Had no difference in self-care, turbulence or responsibility</li> <li>7. Had no differences in number or length of hospitalization</li> </ol> <p><i>Client perspectives:</i></p> <ol style="list-style-type: none"> <li>1. Had fewer unmet practical needs (same as above)</li> <li>2. Had no differences in social networks</li> <li>3. Had no differences in satisfaction with services</li> </ol>
Davidson et al. (2004)	Individual Peer Supporters participating in traditional MHSS	<p><i>Design:</i> Single-program multi-site RCT (<math>n = 260</math>)</p> <p><i>Interventions:</i></p> <ol style="list-style-type: none"> <li>1. Peer support from a consumer-partner with a similar history of psychiatric disability</li> <li>2. Social support from a partner without personal experience of psychiatric disability</li> <li>3. No peer or social support provided</li> </ol>	<ol style="list-style-type: none"> <li>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</li> <li>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</li> <li>3. Depressive symptoms did not improve in any of the three groups (see interventions design)</li> </ol>

Table 2 continued

Study	Consumer involvement	Methods	Between-group differences
Dumont and Jones (2002)	Entirely consumer-run organization	<p><i>Design:</i> Single-center RCT (<math>n = 265</math>)</p> <p><i>Interventions:</i></p> <ol style="list-style-type: none"> <li>1. Access to a consumer-run crisis hostel and peer support as well as traditional hospital-based services</li> <li>2. Access to hospital-based services only</li> </ol>	<p>Those with access to the hostel had:</p> <ol style="list-style-type: none"> <li>1. Significantly less hospital admissions</li> <li>2. Shorter duration of stays in hospitals</li> <li>3. Greater levels of satisfaction with services</li> </ol> <p>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)</p>
Forchuk et al. (2005)	Individual Peer Supporters, a consumer-led service as a partnership within a traditional MHS	<p><i>Design:</i> Single-program cluster randomized study (<math>n = 26</math>)</p> <ol style="list-style-type: none"> <li>1. Transitional discharge model (TDM) with in-patient staff continuing care plus peer support</li> <li>2. Standard model of discharge care</li> </ol>	<p>Discharged patients participating in TDM:</p> <ol style="list-style-type: none"> <li>1. Had no difference in global QoL</li> <li>2. Had a greater improvement in social relations</li> <li>3. Consumed \$4,400 CDN less hospital and emergency room services per person</li> </ol>
Greenfield et al. (2008)	Entirely consumer-run, crisis residential program	<p><i>Design:</i> Multi-center RCT (<math>n = 393</math>)</p> <p><i>Interventions:</i> Solely operated by mental health consumers or received minimal input from professional staff</p> <ol style="list-style-type: none"> <li>1. Experimental condition- consumer-run, crisis residential program, emphasizing client decision, involvement in recovery and also the importance of experiential learning</li> <li>2. Usual care condition- locked, inpatient psychiatric facility, run by medically trained professional staff</li> </ol>	<ol style="list-style-type: none"> <li>1. Greater mean improvement for psychiatric symptoms and strengths, and treatment satisfaction for the experimental group</li> <li>2. Consumer-run, crisis residential services are viable, cost-effective alternatives to more restrictive, traditional, acute inpatient services</li> </ol>
Kaufmann (1995)	Peer Support groups, participating in a traditional MHS	<p><i>Design:</i> Single-center RCT (<math>n = 161</math>)</p> <p><i>Interventions:</i> Employment</p> <ol style="list-style-type: none"> <li>1. Self Help Employment Center (SHEC) providing peer support groups and a consumer-led self help program</li> <li>2. Community vocational services</li> </ol>	<p>Participants attending the SHEC:</p> <ol style="list-style-type: none"> <li>1. Had a higher vocational status</li> <li>2. Took less time to find a job</li> <li>3. Had no difference in average hourly wage</li> <li>4. Did not remain in their jobs for as long</li> </ol>

Table 2 continued

Study	Consumer involvement	Methods	Between-group differences
Klein et al. (1998)	Individual Peer Specialists participating in a traditional MHS	<p><i>Design:</i> Single-centre, single-program RCT (<math>n = 61</math>)</p> <p><i>Interventions:</i> Peer social support program involving:</p> <ol style="list-style-type: none"> <li>1. Intensive case management (ICM) coupled with an individual peer supporter (Friends Connection)</li> <li>2. Intensive case management only</li> </ol>	<p>Clients who received ICM plus a peer supporter:</p> <ol style="list-style-type: none"> <li>1. Had far less crisis events and inpatient days</li> <li>2. Improved in social functioning</li> <li>3. Improved in living arrangements, income and health</li> <li>4. Decreased substance abuse [control group increased]</li> <li>5. Were engaged in fewer community activities</li> <li>6. Had no difference in social interaction</li> <li>7. Had no difference in interaction with friends and family</li> </ol> <p>Cost savings due to the reduction in inpatient days was estimated at US\$22,000/client for 6 months</p>
O'Donnell et al. (1999)	Advocates participating in a traditional MHS	<p><i>Design:</i> Single-centre RCT (<math>n = 119</math>)</p> <p><i>Interventions:</i></p> <ol style="list-style-type: none"> <li>1. Client-focused CM plus consumer advocacy</li> <li>2. Client-focused CM</li> <li>3. Standard case management</li> </ol>	<p>Clients who received client-focused CM plus consumer advocacy:</p> <ol style="list-style-type: none"> <li>1. Had a lower family burden of care</li> <li>2. Had no differences in functioning, disability, QoL, satisfaction with services, burden of care or number of days in hospital</li> </ol> <p>Case manager advocates had higher levels of satisfaction working with clients</p>
Paulson et al. (1999)	Individual Case Managers within an entirely consumer-run MHS	<p><i>Design:</i> Single centre, RCT (<math>n = 5</math>)</p> <p><i>Interventions:</i> Providers of Assertive Community Treatment (ACT) with:</p> <ol style="list-style-type: none"> <li>1. Consumer case managers</li> <li>2. Non-consumer CMs</li> </ol>	<p>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</p> <p>2. The consumer team spent twice as much time in supervision and regularly discussed the impact of job stress on their psychological well-being</p>



Table 2 continued

Study	Consumer involvement	Methods	Between-group differences
Sells et al. (2006)	Individual Case Managers participating in a traditional MHS	<p><i>Design:</i> Single-program, single-center Single-program RCT (<math>n = 137</math>)</p> <p><i>Interventions:</i> Assertive Case Management by:</p> <ol style="list-style-type: none"> <li>1. Peer providers</li> <li>2. Regular providers</li> </ol>	<p>Clients with peer case managers:</p> <ol style="list-style-type: none"> <li>1. Reported feeling more liked, understood and accepted by their providers after 6 months of treatment, but these effects disappeared at 12 months</li> <li>2. Showed increasing contacts with providers over 6 months, (client with case managers showed decreasing contact)</li> </ol>
Solomon and Draine (1995a, b, 1996)	Individual Case Managers, as a consumer-run service	<p><i>Design:</i> Single-centre RCT (<math>n = 96</math>)</p> <p><i>Interventions:</i> Intensive case management with teams of:</p> <ol style="list-style-type: none"> <li>1. Consumer case managers</li> <li>2. Non-consumer CMs</li> </ol>	<p>Consumer managers:</p> <ol style="list-style-type: none"> <li>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</li> <li>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</li> <li>3. Had no difference in the number of service contacts or total units of service</li> </ol> <p>Clients served by consumer case managers:</p> <ol style="list-style-type: none"> <li>1. Had less satisfaction with mental health treatment</li> <li>2. Had less contact with family members</li> <li>3. Had no differences in symptoms, level of functioning, hospitalizations, attitudes to medications, satisfaction with treatment, and QoL</li> </ol> <p>Students who attended IOOV had greater changes in knowledge and attitudes about mental illness</p>
Wood and Wahl (2006)	Individual Educators, as an entirely consumer-run program	<p><i>Design:</i> Single-program RCT (<math>n = 114</math>)</p> <p><i>Interventions:</i></p> <ol style="list-style-type: none"> <li>1. In Our Own Voice (IOOV) a consumer-led anti-stigma program to educate consumers, mental health professionals, students, and police officers</li> <li>2. Presentation on careers in psychology</li> </ol>	

**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	<i>Design:</i> Single center, longitudinal study <i>Evidence level:</i> III-1 (n = 104) <i>Interventions:</i> 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	<i>Design:</i> Single center, comparative study (n = 530) <i>Evidence Level:</i> III-1 <i>Interventions:</i> 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	<i>Design:</i> Multi-center, multi-program longitudinal study (n = 226) <i>Evidence level:</i> III-1 <i>Interventions:</i> 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%) <i>Limit:</i> 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	<i>Design:</i> Single- community psychiatric services, 2-year study (n = 88) <i>Evidence level:</i> III-2 <i>Interventions:</i> 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	<i>Design:</i> Single-program, multi-center, longitudinal study (n = 2,935) <i>Evidence level:</i> III-2 <i>Interventions:</i> 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	<i>Design:</i> Single-center, longitudinal study (n = 158) <i>Evidence level:</i> III-2 <i>Interventions:</i> 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 <i>matched sample of people</i> between two time-points showed there were no differences in the number of re-admissions to hospital or the number of inpatient days

Table 3 continued

Study	Consumer involvement	Methods	Between-group differences
Kane and Blank (2004)	Individual Peer Specialists participating within a traditional MHS	<i>Design:</i> Multi-center, single-program, longitudinal study ( $n = 59$ ) <i>Evidence level:</i> III-2 <i>Interventions:</i> 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	<i>Design:</i> Multi-program longitudinal study <i>Evidence level:</i> III-2 ( $n = 118$ ) <i>Interventions:</i> 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	<i>Design:</i> Single-center longitudinal study <i>Evidence level:</i> III-2 ( $n = 511$ ) <i>Interventions:</i> 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	<i>Design:</i> Single-program, multi-center, longitudinal study ( $n = 269$ ) <i>Evidence level:</i> III-2 <i>Interventions:</i> 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

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

#### 225 *Consumers as Staff Members*

226 O'Donnell et al. (1999) found that consumer advocates had  
227 greater job-satisfaction than non-consumer advocates, and  
228 Solomon and Draine (1996) found that consumer case

229 managers did not show any greater signs of stress, dimin-  
230 ished self-esteem or burnout than traditional staff, although  
231 they were concerned about their acceptance by other  
232 mental health professionals. Paulson et al. (1999), however,  
233 reported that consumer case managers spent more time in  
234 supervision than their non-consumer colleagues and regu-  
235 larly discussed the impact of job stress on their psycho-  
236 logical well-being. The authors stated that "Consumers  
237 may also have limitations as service providers, such as

**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

238 increased vulnerability to the stressful nature of MHS 264  
 239 delivery in general, and case management in particular; 265  
 240 difficulties in maintaining appropriate boundaries and 266  
 241 stigmatization by other mental health professionals” 267  
 242 (p. 253). They mentioned that consumers involved in ser- 268  
 243 vice provision might require special supports to prevent 269  
 244 burn-out or relapse. Chinman et al. (2000), added some of 270  
 245 the potential difficulties that consumer-led services may 271  
 246 encounter, including “role confusion, discrimination from 272  
 247 co-workers, feelings of being a “second class” employee, 273  
 248 and feelings of being under compensated for their work” 274  
 249 (p. 451). On the other hand, they also pointed out the 275  
 250 potential for consumer involvement to create meaningful 276  
 251 employment for people who have a mental illness. 277

252 *Satisfaction with Services* *Clients' Recovery- Emotional, Social, Symptomatic* 278  
 and *Practical Outcomes* 279

253 There is some debate about whether satisfaction with ser- 280  
 254 vices should be used as a mental health outcome measure 281  
 255 (Gordon et al. 2004). Consumers have argued in favor of its 282  
 256 use asserting that consumers have a right to services with 283  
 257 which they are happy and satisfaction is imperative to 284  
 258 achieving full involvement of consumers (Graham et al. 285  
 259 2001). Nine studies measured clients' satisfaction with 286  
 260 consumer-led services compared to usual mental health 287  
 261 services. Six of these studies reported clients to have 288  
 262 greater satisfaction with the consumer-led intervention 289  
 263 (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.

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

Author Proof

- 290 published in 2008 (Castelein et al. 2008; Greenfield et al.  
291 2008) found similar results in that user-led self-help  
292 programs had a positive effect on self-reported and clini-  
293 cian-rated psychopathology and other positive measures  
294 (e.g., quality of life, social network, self-efficacy and  
295 self-esteem). Three studies reported negative findings.  
296 Davidson et al. (2004) found that clients improved in all  
297 three categories if they met regularly with a person from  
298 the general community, but worsened if they met regularly  
299 with a consumer peer supporter. Klein et al. (1998) found  
300 that clients given individual peer support were engaged in  
301 fewer community activities than those without the peer  
302 support. However, sample size for this study was very  
303 limited with only 10 participants in the consumer group.  
304 Solomon and Draine (1995b) found that clients with con-  
305 sumer case managers had less contact with their families  
306 than those with non-consumer case managers. To sum up,  
307 in most studies, clients who used consumer-run or con-  
308 sumer led services consistently had greater improvements  
309 in practical outcomes, including employment (Kaufmann  
310 1995), finances (Craig et al. 2004; Felton et al. 1995; Klein  
311 et al. 1998), education (Nelson et al. 2006b; Ochocka et al.  
312 2006), living arrangements (Klein et al. 1998), and trans-  
313 port (Craig et al. 2004). There is some evidence that  
314 involvement with consumer-staff may restrict the evolution  
315 of natural community and family supports (e.g., Davidson  
316 et al. 2004; Klein et al. 1998).
- 317 *Categories of Outcomes*
- 318 Given the heterogeneity of studies in this field and the lack  
319 of power (due to sample size) to detect an effect, stan-  
320 dardization of outcomes and routine reporting of effect  
321 sizes from individual studies will be crucial for compar-  
322 isons of different models of service delivery. This approach  
323 may also allow for meta-analytic techniques to be utilized  
324 for pooling the results of future studies. Additional out-  
325 comes reported that are missing from the National Out-  
326 comes Measures were emotional and mental recovery  
327 from the clients' perspective, spiritual wellbeing, level  
328 of income, and other practical/living outcomes such as  
329 the need for assistance obtaining meals and groceries.  
330 Although it is necessary to measure outcomes related to the  
331 provision and funding of services, outcomes that are  
332 meaningful to consumers and their quality of life must also  
333 be included (Gordon 2009; Gordon et al. 2004). Internation-  
334 ally a number of different instruments are being  
335 developed and validated for use across countries. For  
336 example, in Australia, Anderson et al. (2006) developed the  
337 Stages of Recovery Instrument (STORI) to measure  
338 recovery as a concept described by consumers. Researchers  
339 have highlighted the critical importance of involving con-  
340 sumers at every stage of the development of relevant
- outcome measures (Allott et al. 2006; Gordon 2006; 341  
Gordon et al. 2004). 342
- Overall Service Outcomes* 343
- The validity of data collection methods by consumer 344  
interviewers compared to staff members within a tradi- 345  
tional mental health service was evaluated in three studies, 346  
all of which found that clients interviewed by a consumer 347  
were more likely to reveal negative responses about satis- 348  
faction with services (Clark et al. 1999; Polowczyk et al. 349  
1993; Uttaro et al. 2004). 350
- In terms of the quality of service, Paulson et al. (1999) 351  
found that the consumer team emphasized 'being there' 352  
with the client while the non-consumer team was more 353  
concerned with accomplishing tasks. Solomon and Draine 354  
(1996) reported a similar finding in that consumer case 355  
managers were more likely to provide face-to-face services 356  
with the client. However, they also found there was no 357  
overall difference in the number of service contacts made. 358  
Young et al. (2005) found that a consumer-run program 359  
had increased competencies on some scales, but not on 360  
others when compared to a traditional MHS. 361
- The majority of studies found a reduction in hospital- 362  
izations (e.g., Chinman et al. 2001; Clarke et al. 2000; 363  
Dumont and Jones 2002; Forchuk et al. 2005; Klein et al. 364  
1998; Nelson et al. 2006a), although one study found no 365  
differences (O'Donnell et al. 1999). Three of these studies 366  
evaluated cost effectiveness based on hospitalization, 367  
finding cost savings per patient [US\$1,169/12 months 368  
(Dumont and Jones 2002), US\$4,400/12 months (Forchuk 369  
et al. 2005), US\$22,000/6 months (Klein et al. 1998)] for 370  
the consumer-led service. The latter of these studies (Klein 371  
et al. 1998) was the least reliable due to the small sample 372  
size. 373
- Conclusions** 374
- To make a strong case for their place in the array of ser- 375  
vices offered by the mental health sector, consumer-led 376  
services are required to demonstrate at least equivalent 377  
effectiveness to a traditional service in regard to outcomes 378  
for clients. Overall, consumer-led services seemed to report 379  
equally positive outcomes for their clients as traditional 380  
services, particularly for practical outcomes such as 381  
employment, income, education or living arrangements, 382  
and in reducing hospitalizations and the cost of services. 383  
Results were varied for client satisfaction and recovery, 384  
and some negative findings were reported. Consumers as 385  
interviewers may increase the validity of reporting on 386  
satisfaction with services. Involving consumers in services 387  
can provide employment opportunities and is both 388

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

#### 401 Limitations

402 This review used a structured approach to review the lit-  
 403 erature and the scope was confined to an examination of the  
 404 effectiveness of the service or program. Although this  
 405 review does not consider the acceptability of the service to  
 406 users or funders, or any ethical, economic or legal con-  
 407 siderations associated with consumer-led services, these  
 408 are important issues worthy of further study. The majority  
 409 of the reviewed articles were written by health profes-  
 410 sionals, with or without input from consumers, which  
 411 might have influenced the studies design and the choice of  
 412 outcomes measured. The studies included in the present  
 413 review were conducted in high-income, English speaking  
 414 countries therefore the findings may not be generalizable to  
 415 countries where low incomes or different cultural influ-  
 416 ences or approaches to mental health predominate. Descrip-  
 417 tive or qualitative studies were not included as they are not  
 418 designed to quantify the effectiveness of services. However,  
 419 qualitative research is useful in providing a rich description  
 420 of how consumer-led services are delivered, the unique  
 421 experience and perceptions of service providers and con-  
 422 sumers, and the specific context of individual programs.

#### 423 Future Research

424 Research in the future needs to incorporate standardized  
 425 outcomes, including a core set of primary outcomes which  
 426 are consistently reported by all investigators. Indeed some  
 427 outcomes consumers identified as important, for example  
 428 whether or not they have achieved their own goals, leisure  
 429 time, access to legal aid, and family burden (Rapp and  
 430 Goscha 2006), were missing altogether from the studies we  
 431 reviewed. Another important line of investigation is to  
 432 examine how the intervention process (e.g., level of self-  
 433 disclosure, or giving help) relates to outcomes. Most  
 434 studies did not measure long term effects, particularly  
 435 following the conclusion of a program, and they rarely  
 436 addressed concerns raised in the literature about issues

such as confidentiality, participants' level of attendance 437  
 during the course of study, suitability of suggestions made 438  
 by consumer-staff (Crawford and Rutter 2004), and the 439  
 level of evidence-based practice (Summers 2003). These 440  
 barriers need to be addressed to allow for consumer 441  
 involvement in services, and some form of standard 442  
 training may need to be implemented. 443

There were a limited number of studies on consumer-led 444  
 services as partnerships with traditional services, and no 445  
 studies that measured outcomes based on the level of par- 446  
 ticipation of the consumers. There were no studies, for 447  
 example, that looked at service reform with consumers in a 448  
 position of funding or policy planning of a traditional MHS. 449  
 Goldstrom and associates (2006) also found that traditional 450  
 and consumer-led services were really still two distinct 451  
 entities. To date there is no published study to compare roles 452  
 of consumers, for example consumers as case managers 453  
 versus peer-specialists. For research to advance we also need 454  
 to agree on uniform definitions of consumer-led services, 455  
 and we need to adopt a partnership approach to conducting 456  
 the research. Both qualitative and quantitative methodology 457  
 can be used, but both must be implemented robustly as well 458  
 as consumer driven, that is instigated, organized and 459  
 reported by consumers. Well-designed, longitudinal effec- 460  
 tiveness studies would be useful for addressing the lack of 461  
 data on longer-term outcomes. 462

Chen (1990) suggests that evaluators should first address 463  
 whether programs are serving their targeted beneficiaries, 464  
 with service delivery activities and programs as intended, 465  
 and meeting their specified objectives. Once this is assured, 466  
 experimental designs for outcome evaluation may be con- 467  
 sidered, but not before. Otherwise it cannot be known 468  
 whether unsuccessful outcomes reflect failure of the spec- 469  
 ified model or failure to implement the model as speci- 470  
 fied. We recommend that due to the high drop-out rates in 471  
 primary research of this topic, both an 'intention to treat' 472  
 and 'as-treated' analyses need to be done. Also, although 473  
 tricky, where feasible the participants should be blind to 474  
 which service they are receiving, as was done in the study 475  
 by Forchuk and colleagues (2005). 476

Lastly, consumers should determine the style of con- 477  
 sumer-led services to be developed. Health professionals, 478  
 researchers and policy planners can advocate for the con- 479  
 tinued support of existing consumer providers and can 480  
 assist in the development of new services through the 481  
 provision of material resources, ongoing support and 482  
 workforce training. Ultimately, as Mowbray and Tan 483  
 (1993) suggest, it is the mental health consumers them- 484  
 selves who will create the services and make them work. 485

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