
The Effectiveness of Service User-Run or Service User-Led Mental Health Services for People with Mental Illness

A Systematic Literature Review

CAROLYN DOUGHTY
SAMSON TSE

Published by the
Mental Health Commission
Wellington, New Zealand
2005
ISBN: 0-478-29204-X

**Mental
Health**
COMMISSION

This report should be referenced as follows:

Doughty, C., Tse, S. (2005) The effectiveness of service user-run or service user-led mental health services for people with mental illness:
A systematic literature review. Wellington, New Zealand: Mental Health Commission.

The effectiveness of service user-run or service user-led mental health services for people with mental illness

A Systematic Literature Review

Carolyn Doughty
Samson Tse

This report should be referenced as follows:

Doughty, C., Tse, S. (2005) The effectiveness of service user-run or service user-led mental health services for people with mental illness: A systematic literature review. A Mental Health Commission Report; Mental Health Commission, Wellington, New Zealand.

ACKNOWLEDGEMENTS

This report was prepared by Dr Carolyn Doughty (National Coordinator, Balance NZ - Bipolar and Depression Network and Research Fellow, Christchurch School of Medicine and Health Sciences, University of Otago) and Dr Samson Tse (Associate Dean [International], Faculty of Medical and Health Sciences and Senior Lecturer in Mental Health Development, University of Auckland). Margaret Paterson (Information Specialist) from New Zealand Health Technology Assessment, Christchurch School of Medicine and Health Sciences (University of Otago) developed and undertook the search strategy, produced an information package for the Mental Health Commission and coordinated the retrieval of documents. External peer review was provided by Shery Mead, New Hampshire, United States of America. Internal peer review was provided by Debbie Peterson, Mental Health Foundation, Wellington, New Zealand. Final sub-editing was done by Kathy Doughty and formatting by the Mental Health Commission. This report was commissioned by Mary O'Hagan and Jan Dowland (Mental Health Commissioners) of New Zealand's Mental Health Commission. We thank Alex Handiside, Hilary Lapsley and Mary O'Hagan for assisting in developing the scope of this report and Helen Gilbert for assistance in identifying some of the current service user-run and service user-led services or initiatives within New Zealand.

CONFLICT OF INTEREST STATEMENT

The principal author (CD) is employed half-time as the National Coordinator of a service user-run organisation that was contracted by the Mental Health Commission to prepare this report. She is also employed half-time as a researcher in the Department of Public Health and General Practice (New Zealand Health Technology Assessment), Christchurch School of Medicine and Health Sciences, University of Otago.

The second author is employed full-time by the University of Auckland and he declares no conflict of interest to this literature review.

Contact Details (Principal author)

Dr Carolyn Doughty
Balance NZ - Bipolar and Depression Network
PO Box 13266
Christchurch
New Zealand

Tel: +64 3 366 3631
Email: bipolar@balance.org.nz
Website: www.balance.org.nz

FOREWORD

Peer run services are beginning to establish themselves throughout the world and recently have been described in the US Surgeon General's report as an essential ingredient in many people's mental health recovery. Emerging evidence indicates that people who work and/or participate in peer operated programmes are stronger self advocates, more engaged in recovery practices, and are building new roles that help establish meaningful community integration. However, with this movement towards legitimising and funding peer programmes, it is crucial that we understand what makes for 'good' peer support.

Peer support is a quality of being with people who have shared life experiences. This quality generally includes mutual support and has the expectation of critical learning and consciousness raising. Because peers offer each other a unique framework for understanding 'problems,' (e.g. a non-medical approach) they are able to listen from a neutral frame of reference while challenging each other to explore old patterns and habits. It is in this context of mutual help that many people are then able to do together what was not so easy to try alone. Out of this experience comes not only greater recovery for both peers but a sense of value at having been both helper and helped. It begins to create awareness that there are many ways of understanding our experiences and many creative solutions for solving problems. Peer support then begins the natural process of building community while helping people move beyond their previously held self definition. And it is here in community that peer support offers its most significant attribute: real social change.

Shery Mead, Consultant, New Hampshire, USA, co-author with Mary Ellen Copeland of *WRAP and Peer Support Manual: Personal, Group and Program Development* (2004).

There has been a quiet revolution happening in New Zealand. While the rest of the country has been paying attention to other things, support services run by and for people with experience of mental illness have been developing. There are now at least thirty-five or more of them (listed as an appendix to this report). They exist despite difficulties in finding funding, to give people another choice – the choice to have our mental health and advocacy services delivered by our own experts – people with experience of mental illness.

While we are becoming expert in setting up services run by and for people with experience of mental illness, we have not yet become experts in evaluating them. With this systematic review we now have an excellent insight into the evaluation of such services, but one of the findings is that there is a lack of evaluation material from New Zealand. We cannot rely solely on overseas studies to tell us whether services run by and for people with experience of mental illness are effective here in New Zealand. It is time to undertake our own research. Just what form this research should take needs to be debated. Do we try for the gold standard of the randomised control trial, or do we recognise the limitations of this approach and look at more descriptive studies?

What ever we decide to do, it is clear that the development of services run by and for people with experience of mental health services will continue. The opportunity is there to provide a real difference in the way mental health and advocacy services are provided here in New Zealand, giving people with experience of mental illness a real choice.

Debbie Peterson, Senior Policy Analyst/Researcher, Mental Health Foundation of New Zealand.

EXECUTIVE SUMMARY

Aim

The main objective of this report is to systematically identify and appraise the international evidence for the effectiveness of service user-run or service user-led mental health services for people with mental disorders.

A service user-run, service user-led service is defined as a programme, project, or service planned, administered, delivered, and evaluated by a service user group based on needs defined by the service user group. Operation of the service requires self-governance by service users themselves, service user staffing and supervision of this staff, service user control of programme policy, and service user responsibility for programme implementation.

This report seeks to highlight the potential for investment in, and future evaluation of, service user-run initiatives and services within the mental health sector.

Methods and Key Results

The literature was searched using the following bibliographic databases: Medline, PsychInfo, Embase, Current Contents, Cinahl, Web of Science and Index New Zealand.

In the preliminary search undertaken for this review, additional sources searched included major online library catalogues, website sources such as evidence-based and guidelines sites, government health websites, related health professional association websites, and major websites. Other electronic and library catalogue sources searched included: the Cochrane Library and Database of Abstracts of Reviews of Effectiveness. Several Internet websites were also searched to access organisations with a focus on mental health service users. In New Zealand, databases were accessed from the National Bibliographic Database, Ministry of Health website and library, university and medical library catalogues and the New Zealand Health Technology Assessment unit's in-house collection. Relevant publications referenced in material obtained in the course of research on the topic were also identified.

Searches were limited to English language material from 1980 to May 2004 inclusive. Studies were included if they described or evaluated a service user-run or service user-led service.

Excluded retrieved articles included abstracts and correspondence; background studies, book chapters, unpublished reports and case studies or series.

A systematic method of literature searching, selection and appraisal was employed in the preparation of this report. Studies are summarised (using the spelling of the original article) and presented by study design, and for each type of study design, alphabetically by the lead author.

Of more than 175 articles identified by the search strategy, 85 articles were retrieved as full text from which a final group of 26 primary data papers and two systematic reviews were identified as eligible for appraisal and inclusion in the review.

Conclusions

Overall, research on consumer services reports very positive outcomes for clients. This review of effectiveness found some studies that reported higher levels of satisfaction with services, general wellbeing and quality of life while others reported no significant differences between service user-run services and mental health services run by non-service user providers. No studies reported evidence of harm to service users or that consumer services were less effective than the equivalent services offered within a traditional setting.

The evidence base supporting the effectiveness of service user-run services is gradually expanding. The findings to date have to be interpreted with caution as the majority of service user-run services identified by this review were operated alongside clinical staff, peer specialists on case management teams or crisis teams. This implies that the setting in which studies were conducted fulfils the definition of a consumer provided or partnership service but may not meet the more stringent operational definition of a consumer run service in terms of the level of autonomy, self-governance and the level of consumer control required. The positive effect on outcomes could potentially be greater for consumer run services than those with a participation model of consumer involvement. This is as yet unknown. Therefore it is vitally important that in the future effectiveness research measuring meaningful outcomes for

service users is carried out on a wider range of different models or types of services in existence and that any differences in effect are formally evaluated.

Consumer-run services worldwide receive very limited funding from mental health budgets despite a growing trend that suggests they may represent an effective model of mental health service delivery. Furthermore, to justify their place in the array of services offered within the mental health sector, a strong case can be made that services should only be required to demonstrate equivalent effectiveness compared with traditional services rather than superiority in regard to outcomes for clients.

At present there is a mixed record of research on service user delivered services and more research on the effectiveness of these services is urgently needed to establish a broader evidence base for policy and advocacy. Despite a great deal of prior descriptive work that supports the feasibility of consumer provided services only a limited number of controlled studies have been published focusing on outcomes for people who participate in, or receive care or support from, these services. To date, there is very little evaluative work that has been done in this area in New Zealand.

The potential already exists for New Zealand specific research and evaluation of service user-run, service user-led services but to achieve this goal, a full range of service user-run or led services, need to be developed, piloted and funded in a sustainable way.

TABLE OF CONTENTS

Acknowledgements	2
Conflict of interest statement	2
FOREWORD	3
Executive summary	4
<i>Aim 4</i>	
<i>Methods and Key Results</i>	4
<i>Conclusions</i>	4
Table of Contents	6
List of Tables	7
1. INTRODUCTION	10
1.1 Objective.....	10
1.2 Scope of report.....	10
1.3 Structure of report	10
2. BACKGROUND.....	11
2.1 Definition of service user.....	11
2.2 Definition of service user-run or service user-led service	12
2.3 Models of service user involvement	12
2.4 Consumer services or initiatives in New Zealand.....	14
3. Methods	15
3.1 Selection of studies	15
3.2 Search strategy	16
3.3 Study selection	16
3.4 Appraisal of studies.....	18
3.5 Key outcome measures for primary studies.....	18
4. Results	19
4.1 Identification of eligible papers	19
4.2 Secondary research.....	19
4.3 Primary research	23
4.3.1 <i>Study setting</i>	23
4.3.2 <i>Samples</i>	23
4.3.3 <i>Interventions</i>	23
4.3.4 <i>Outcomes</i>	24
4.4 Primary research: study results	24
5. DISCUSSION	51
5.1 Summary of evidence	51
5.1.1 <i>Descriptive studies</i>	51
5.1.2 <i>Comparative studies</i>	53
5.1.3 <i>Controlled studies</i>	54
5.2 Limitations of the review	55
5.3 Directions for future research	57
5.3.1 <i>Key international research</i>	57
5.3.2 <i>New Zealand research</i>	57
6. Conclusions	58
BIBLIOGRAPHY	59
Appendix One Service user-run or led mental health services in New Zealand	67
Appendix Two Search Strategies	70

LIST OF TABLES

Table 1.	Ways in which service users can be involved in mental health services	14
Table 2.	Examples of service user involvement in New Zealand	14
Table 3.	Study designs included in this literature review	15
Table 4.	Explanation of the levels of evidence specified.....	15
Table 5.	Strength of evidence	16
Table 6.	Inclusion/exclusion criteria for identification of relevant studies	17
Table 7.	Involving service users in the delivery and evaluation of mental health services (secondary research).....	20
Table 8.	Brief summary of a range of controlled studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level II)	25
Table 9.	Brief summary of a range of comparative studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level III)	31
Table 10.	Brief summary of a range of descriptive studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level IV).....	38

LIST OF ABBREVIATIONS (*spelling as per original article*)

ACCESS	Access to Community Care and Effective Services and Supports
ANOVA	Analysis of Variance
ASFS	Assisted Social Functioning Scale
BPRS	Brief Psychiatric Rating Scale
CCS	Community and Consumer service
CDS	Consumer-Delivered Services
CES-D	Centers for Epidemiological Studies Depression Scale
Cinahl	Cumulative Index to Nursing and Allied Health Literature
CMHA	Community Mental Health Agency
CMHC	Community Mental Health Centre
COPEs	Community-Oriented Program Environment Scale
COSP	Consumer-Operated Services Program
CRCL	Consumer-Run, Consumer-Led
CRO	Consumer-Run Organization
CSQ	Consumer Satisfaction Questionnaire
DSM-III	Diagnostic and Statistical Manual of Mental Disorders 3 rd Edition
DSM-III-R	Diagnostic and Statistical Manual of Mental Disorders 3 rd Edition Revised
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders 4 th Edition
GESF	Group Environment Scale Form
HPCS	Health Problems Checklist Score
HS	Hope Scale
ICD-10	International Classification of Diseases 10 th Edition
ICM	Intensive Case Management
ILC	Independent Living Centre
ISFA	Independent Social Functioning Scale
LCS	Locus of Control Scale
MEI	Mind Empowered Inc
MHC	Mental Health Commission
NAMHSCA	National Association of Mental Health Services Consumer Advisors
NGO	Non-Government Organisation
NHMRC	National Health and Medical Research Council
NIMH	National Institute of Mental Health
NZHTA	New Zealand Health Technology Assessment
PES	Empowerment Scale
PSS	Peer Support Specialists
QOL	Quality of Life
RCT	Randomised Controlled Trial
RSES	Rosenberg Self-Esteem Scale
SH	Self Help
SHA	Self Help Agency
SHASS	Self-Help Agency Satisfaction Scale

SL	Stressful Life Events in Previous Month
SU	Services Used in Previous Six Months
WBP	Welcome Basket Program

1. INTRODUCTION

1.1 Objective

The purpose of this report is to systematically identify and appraise the available, published international evidence for the effectiveness of service user-run or service user-led mental health services for people with mental disorders. It also seeks to provide a brief synthesis of the broader literature describing consumer involvement in education, peer support and advocacy in mental health in New Zealand.

Systematic reviews are a specific type of literature review. They aim to evaluate and summarise relevant primary sources of research, often randomised controlled trials but also other study designs. They are particularly useful because they contain explicit statement of objectives, sources used and methods; they have been conducted according to an explicit methodology and are therefore reproducible. Systematic reviews derive much of their credibility from the fact that they bring together a wide range of research studies but they are also not based on simply one individual's opinion of the current state of knowledge, which however authoritative will inevitably come from a limited and partial perspective. The methodological quality of secondary sources of evidence is crucial: a systematic review cannot be more reliable than the primary sources it summarises, but it can be less reliable. Thus it is clearly important for reviewers to evaluate the evidence they include very carefully.

1.2 Scope of report

This systematic review was requested by the Mental Health Commission who helped to develop the scope of the report. It seeks to inform service users, service providers and those who develop, plan and purchase services and those who determine policy and legislation.

Studies were included for review if they reported on the effectiveness of service user-run or service user-led mental health services for people with mental disorders. The search was limited to articles published in English and published between January 1980 and May 2004. Full details of inclusion and exclusion criteria are provided in the methods section.

1.3 Structure of report

This report is divided into sections that describe background, methodology (search strategy, inclusion and exclusion criteria, and outcomes considered), results (primary and secondary research included). Results include tables outlining the best available evidence, which present each appraised study's methods, results, limitations, and authors' conclusions. The final section summarises results, briefly discusses methodological limitations in the area, and presents key conclusions.

2. BACKGROUND

'Recovery' is defined in the Mental Health Commission's Blueprint for Mental Health Services (1998) as the ability to live well in the presence or absence of one's mental illness (or whatever people choose to name their experience). Each person with mental illness needs to define for themselves what 'living well' means to them. The definition is purposefully a broad one, because the experience of recovery is different for everyone and a range of service models could potentially support recovery.

O'Hagan (2000) suggests that the recovery approach requires mental health services to develop and draw on their own resources, but it also requires that they develop and draw on the resources of people with mental illness and their communities. That is, recovery happens when people with mental illness take an active role in improving their lives, when communities include people with mental illness, and when mental health services can enable people with mental illness and their communities and families to interact with each other. A recovery approach may be more compatible with community-based models of service provision than institutionally-based ones.

Among the wide range of community-based models of service provision that exist, are those that can be identified as service user-run or user-led (Clay et al. 2005; Davidson et al. 1999; Mowbray et al. 1997) This report looks at the international literature that describes service user-run services as a model of service delivery, with an emphasis on any studies that examine the effectiveness of such services by reporting relevant outcomes.

To date, most of the literature on service user-run services in mental health, like that of recovery comes from the United States and shares the same three main ideological sources. The first is the generic recovery or self-help movement. The second source is the mental health service user movement, and its underlying philosophy of human rights and self-determination. The third source is psychiatric rehabilitation with its focus on community integration and overcoming functional limitations (O'Hagan 2000; Chamberlin 1977).

2.1 Definition of service user

Who are service users? Consumers themselves do not even have consensus about either terminology or definitions. Corrigan and Garman (1997) suggests that unlike the diagnostic categories set forth in the DSM-IV, no set of definitive terms or criteria is generally accepted as defining or describing mental health consumers. Indeed the concept of exclusionary criteria seems contradictory to the inclusionary spirit of the empowerment movement. For the purposes of this report service users are defined as individuals with mental illness who have been users of mental health services and who identify themselves as such. This is similar to the definition used by Solomon and Draine (2001) all bar the use of the word 'serious' to preface mental illness. Previous reports use similar definitions that clarify some of the ways in which service users may differ (Mental Health Commission 2002). The terms service user, consumer/tangata whaiora are used interchangeably within this report as an acknowledgement of the fact that there is still wide variation in how individuals prefer to be addressed (Mueser et al. 1996). Some advocates are skeptical of the term consumer due to the implication that consumers have 'choices and power' when frequently this is not the case. In the context of this report, however, this term is retained in the majority of evidence tables because it is widely recognised and used in a number of mental health settings and in almost all of the literature from the United States. In the United Kingdom and Europe the term 'service user' is in more general use and in New Zealand the term 'tangata whaiora' (person seeking wellness) or tangata motuhake (another term for people with mental illness) are popular alternatives.

2.2 Definition of service user-run or service user-led service

It is not straightforward to define or even recognise what a service user-run or service user-led service is. To date most operational definitions that have been suggested seem to include the notion that supports are not controlled or dominated by professionals. This does not necessarily preclude non-service users or professionals from being involved, but the inclusion of non-service users is within the control of service user operators (Solomon and Draine 2001). Therefore, for the purposes of this report, service user-run or service user-led services will indicate any service and support service users themselves initiate, plan, organise, deliver and evaluate. To understand the potential impact of service user-run services on the current mental health sector, it is useful to portray how people often report their experiences of the more traditional services on offer, for example case management, therapy, and other interventions. While there is generally consensus among service users that traditional service system staff are on the whole well-intentioned, system structures, resource allocation and general attitudinal issues still interact to create barriers for effective service delivery (MacNeil and Abbott 2000).

2.3 Models of service user involvement

Over the last two decades further effort has been made to empower people with personal experience of mental illness to increase their activity in and control over mental health services (Clay et al. 2005; Davidson et al. 1999; Mowbray et al. 1997). The idea of service user participation in mental health service provision is increasingly accepted in New Zealand and overseas (Mental Health Commission 2002). The notion that service users can participate and provide useful services to other people has been based on two important foundations.

Firstly, mental illness or problems associated with mental illness are seen as being socially constructed (Hutchison & Pedlar 1999). Chinman and his colleagues (2001) examined concepts used to describe people who have serious mental illness and typically receive long-term care in public mental hospital for most of their adulthood. They argued against some of the terminology that has been previously used. A proportion of any individual's ongoing symptoms or psychiatric disability may stem from the "poor person-environment fit between the multiple and complex needs of those with serious psychiatric disorders and the community-based mental health systems" (Chinman, Weingarten, Stayner & Davidson 2001). Therefore service users who collectively work together in roles of service provision are in an ideal position to close the gap of person-environment fit and address an array of issues faced by service users on a day-to-day basis such as social isolation, demoralisation, poor quality of life, and difficulties in accessing mental health services.

Secondly, many accept that because of service users' personal experiences with mental illness and the mental health system, they can make unique contributions to develop and enhance service effectiveness and improve outcomes for mental health clients. The potential benefits include but are not limited to: role modelling recovery, instillation of hope, providing empathy and emotional support, sharing practical information and coping strategies, and strengthening social supports (Felton et al. 1995). Service users as mental health service providers are sometimes seen as more sensitive, as they more readily see the person rather than the illness and relate to what the clients have to say. Employing service users or consumer organisations as providers can facilitate cultural change within mental health workplaces by stimulating open dialogues on the attitude and behaviours of mental health professionals. It helps the mental health system to provide more client-focused health services. It also promotes a vision of inclusion and the full participation of service users in society. It is demonstrated by the fact that mental health services value and employ mental health consumers in providing services to others (Solomon & Draine 2001).

However, despite the claims made about the desirability of service users' involvement, it remains a challenge to define what is meant by involving consumers in mental health services in the New Zealand context. Information on the strength of evidence about the effectiveness of such practice (internationally and nationally) is required to underpin how service user-run or service user-led services could add value to existing mental health services in New Zealand. Perhaps, the current state in the development of consumer participation in mental health

services is best captured by Conner (1999, p.79) as “I often think of it as having reached adolescence, warts and all. Just like adolescents, service users are ‘finding their feet’, exploring the boundaries, and taking risks. This is a healthy and necessary part of growth but can seem chaotic in the process towards collaboration and true partnership”.

A number of strategies have been suggested in the literature (Chinman, Rosenheck, Lam & Davidson 2000; Conner 1999; Hopton & Nolan 2003) to enable an effective consumer partnership model:

- commitment of service providers and service users towards making consumer participation work
- using a range of approaches including informal options to create collaboration between service users and service providers
- a willingness of service providers to listen and act in relation to consumer views
- defining clear and mutually understood objectives and roles for service users in mental health services
- supporting consumer representatives
- running service user-friendly meetings
- dealing with issues like role confusion, discrimination from co-workers and feelings of being a “second class” employee in the mental health system due to being undercompensated or not paid at all for their work.

Consumer provided services are defined as mental health services provided by service users who are intentionally employed to deliver services to others. This definition generally does not include self-help support groups but may include some self-help associations or organisations funded to provide services to consumers that may include the provision of support groups. The varying degree of service user-provided services could be summarised as either consumer partnership services or consumer-run or operated services (Chinman et al., 2000; Simpson & House, 2002; Solomon & Draine, 2001).

Consumer partnership services are defined as services or mental health programmes within non-consumer operated agencies. This model usually refers to service users employed in traditional mental health agencies filling either specialised service positions or usual positions designated for consumers. The positions usually require service users to be overtly identified as such but, in some cases, consumers are integrated with the staff and are not openly identified. However the assertion that consumers are being empowered to have a greater level of input into the design and delivery of mental health services has its own faults. McLean (1995, p.1067) quoted one of her research participants’ remarks: “consumer empowerment may increase people’s options within the mental health system, but true empowerment can never rest in that system”. This kind of frustration or disenfranchisement is further intensified by the influence of social constructionism and post-modernism (Emerick 1991; Peck, Gulliver & Towel 2002). Social constructionism, is the thesis that all knowledge is constructed – given shape and meaning – by members of a “community of speakers”. Consumers as a community of speakers have emphasised how their experience and lived expertise have to be acknowledged. Postmodernism questions the existence of a unitary truth about human existence and has made both science and health practices less authoritarian and more open to knowledge based on lived experiences. The role of professionals in delivering the majority of mental health services is coming under increasing scrutiny and the pervasiveness of the medical model is being challenged. All these lead to the formation of consumer run or operated services.

Consumer run or operated services are defined as services that are planned, operated controlled and evaluated by service users based on needs defined by the service user group, which do not preclude non-consumers or professionals from being involved. But the inclusion of non-consumers is within the control of consumer operators (Solomon and Draine 2001). Rowland et al. (1993) suggests that operation of the service requires self-governance by consumers themselves, consumer staffing and supervision of this staff (including hiring and firing), consumer control of programme policy, and consumer responsibility for programme implementation.

There are a variety of ways in which involvement is possible in both consumer partnership services or consumer-run or operated services and these basic categories are summarised in **Table 1**.

Table 1. Ways in which service users can be involved in mental health services¹

Current or former service user	<p>Provider in traditional mental health services e.g., case manager, client advocate, mental health support worker along with clinical staff, peer specialist on case management team or crisis team</p> <p>Provider of independent mental health service e.g. peer support, information and advocacy services</p> <p>Trainer of mental health service provider/family or carers/other consumers e.g., undergraduate health professional training programme, health professionals' ongoing education, peer support or self management/recovery training</p> <p>Research, audit or evaluation of mental health services</p> <p>Advisors in public policy and programme development</p>
--------------------------------	--

¹ Modified from Simpson and House (2002).

2.4 Consumer services or initiatives in New Zealand

A list of recently identified service user-run, service user-led services or initiatives active in New Zealand is included in **Appendix One**. This includes mainstream services, funded and voluntary service user-run services and “boutique” providers offering particular services within a given locality. This list does not purport to be a comprehensive list as no formal database is available that would allow us to identify all such services but it serves to illustrate the breadth and range of services already operating that could be among those developed in the future.

Table 2. Examples of service user involvement in New Zealand²

Levels of interaction	Conceptions of service user involvement		
	Recipient of communication	Subject of consultation	Agent in control
Interaction between service users	<p>Newsletters</p> <p>Periodicals</p> <p>Community meetings</p>	<p>Advocacy schemes</p>	<p>Workshops</p> <p>Newsletters</p> <p>Periodicals</p>
Interaction between service users and professionals	<p>Receiving “care plans”</p> <p>Crisis intervention plan</p> <p>Advance directives</p>	<p>Agreeing on “care plans”</p>	<p>Direct payments</p> <p>Consultancy services</p>
Management of local services	<p>Receiving information services</p>	<p>Service user representatives sitting on management boards</p> <p>“Patient/Consumer” councils</p> <p>Satisfaction surveys</p> <p>Service user-surveys</p> <p>Consumer-focused monitoring/auditing</p>	<p>Consumer-run houses/drop in centres etc</p> <p>Peer support networks and advocacy</p>
Planning of overall services	<p>Community “care plans”</p> <p>Receiving notices about community projects related to mental health</p>	<p>Service user to represent the voice of people with disability in local community or city council</p>	

² Modified for the New Zealand context from Peck, Gulliver and Towel (2002).

3. METHODS

3.1 Selection of studies

Peer reviewed studies were considered for this review if they used one of the study designs outlined in **Table 3**.

Table 3. Study designs included in this literature review

Systematic review (SR) of studies eligible for inclusion in this review (including those applying broader inclusion criteria)

Randomised controlled trials (including cross-over trials)

Pseudorandomised controlled trials (alternate allocation or some other method)

Concurrent controls or cohort studies

Case-control studies

Cross-sectional or descriptive studies

Evidence obtained from case studies where there is no outcome data was excluded but these are listed in the bibliography. Descriptive studies where there is no control group have been included but are tabled separately from controlled studies (ie. the best evidence for effectiveness). Any identified unpublished or 'grey' literature was included for New Zealand and Australian specific studies but only where they met selection criteria.

Table 4. Explanation of the levels of evidence specified¹

Level of evidence	Study design
I	Evidence obtained from a systematic review of all relevant randomised controlled trials
II	Evidence obtained from at least one properly-designed randomised controlled trial
III-1	Evidence obtained from well-designed pseudorandomised controlled trials (alternate allocation or some other method)
III-2	Evidence obtained from comparative studies (including systematic reviews of such studies) with concurrent controls and allocation, not randomised, cohort studies, case-control studies, or interrupted time series with a control group
III-3	Evidence obtained from comparative studies with historical control, two or more single arm studies, or interrupted time series without a parallel control group
IV	Evidence obtained from case series, either post-test or pre-test/post-test

¹ Modified from (National Health and Medical Research Council 2000).

The strength of the evidence presented in the selected studies will be assessed and classified using the dimensions of evidence defined by the National Health and Medical Research Council (NHMRC, 2000). These are derived directly from the literature identified as informing a particular intervention. The designations of the levels of evidence are shown in **Table 4** and the three subdomains (level, quality and statistical precision) are collectively a measure of the strength of the evidence (see **Table 5**).

Table 5. Strength of evidence

Strength of evidence	Definition
Level	The study design used, as an indicator of the degree to which bias has been eliminated by design.*
Quality	The methods used by investigators to minimise bias within a study design.
Statistical precision	The p-value or, alternatively, the precision of the estimate of the effect. It reflects the degree of certainty about the existence of a true effect.

*See previous page, Table 4

3.2 Search strategy

A systematic method of literature searching and selection was employed in the preparation of this review. Searches were limited to English language material published from 1980 onwards. The searches were completed in May 2004. See **Appendix Two** for the search strategies.

Material referenced in publications obtained in the course of research on the topic were also scanned by the principal author to identify potentially eligible papers. Manual searching of journals, the contacting of manufacturers, or contacting of authors for unpublished research were not undertaken in this review.

3.3 Study selection

Studies were selected for appraisal using a two-stage process. Initially, the titles and abstracts (where available) identified from the search strategy, including references cited in retrieved papers and review articles, were scanned and excluded as appropriate. The full text articles were retrieved for the remaining studies and these were appraised if they fulfilled the study selection criteria outlined above.

Study inclusion and exclusion criteria are described in **Table 6**.

Table 6. Inclusion/exclusion criteria for identification of relevant studies

Characteristic	Criteria
Inclusion criteria	
Publication type	Studies published between 1990 and May 2004.
Sample characteristics	Adults (aged 18 years or more). Study population those with Axis I psychiatric disorders as classified by DSM-IV and/or ICD-10 or earlier versions of these classifications. Studies that were not restricted to participants within these age ranges, but met any of the following criteria: results were reported separately on a subgroup of participants aged at least 13 years of age; the mean age for the sample was at least 13 years.
Sample size	Studies with sample size of 5 or more people.
Intervention/test	Service user-run or service user-led mental health services for people with mental disorders. Comparative or controlled studies of consumer participation services within mental health services where led by consumer steering group, managed, implemented or staffed primarily by service users.
Comparators	Health professional-run and/or directed mental health services.
Outcome	Studies using at least one outcome measure examining the effectiveness of the intervention in achieving improvement in function or quality of life for consumers using the service, studies looking at service delivery or studies looking at indirect measures of effectiveness.
Exclusion criteria	
Publication type	Non-systematic reviews, letters, editorials, expert opinion articles, comments, book chapters, articles published in abstract form and studies on animal subjects. Non-published work.
Language	Non-English language articles will be excluded.
Study design	Evidence obtained from case studies/series/descriptive studies where there is no outcome data.
Sample	Studies which report outcomes for a study population including 50% or more with DSM IV alcohol or drug abuse and/or dependence as the presenting diagnosis will be excluded. Studies which primarily concern participants with physical conditions such as multiple sclerosis or other mental health issues such as bereavement and life stress. Studies on self-help support and advocacy groups where these groups are not clearly part of service user-run or service user-led service or organisation.
Intervention/test	Studies investigating consumer involvement in mental health services but where health professionals retain 50% or more of the role of governance or management of the specific service or event (not including overall governance of the wider mental health service within which an initiative might be placed).
Outcome	Studies which did not use any quantitative outcome measure or proxy measure for collecting and reporting data from study participants.

3.4 Appraisal of studies

The studies are classified according to National Health and Medical Research Council (NHMRC, 2000) levels of evidence criteria, so as to rank them in terms of quality according to a pre-determined “evidence hierarchy” (see **Table 4**). These evidence levels are only a broad indicator of the quality of the research. The levels describe groups of research, which are broadly associated with particular methodological limitations. However, these levels are only a general guide to quality because each study may be designed and/or conducted with particular strengths and weaknesses. High-level evidence is provided by a well-conducted randomised-controlled trial comparing an intervention (eg. mental health service delivered by consumers) of interest and a control (eg. usual care which might be a mental health service delivered by professionals).

Summaries of appraisal of primary studies are presented in tables and include the source (authors and publication), design, objectives and methods of study, main results and author’s conclusion. Additional comments are made in relation to the studies, strengths and limitations. The evidence level is listed in the **Bibliography**, where included studies are marked by an asterisk.

Systematic reviews are described and critiqued in terms of their search strategy, inclusion/exclusion criteria, data synthesis and interpretation. Note that such papers are considered principally as background information as they may not use the same selection criteria as this review and do not consider subsequently published research.

3.5 Key outcome measures for primary studies

Key outcomes using standardised and/or quantitative or proxy measures related to the effectiveness of relevant interventions, including but not limited to improved income, level of functioning, quality of life, attitudes to use of medication, social contacts, symptoms, inpatient days, clients’ satisfaction or perception of the service, hospital admissions, nature or duration of hospitalisation/s, time until first hospitalisation, arrest, emergency hospital care or homelessness, use of crisis services, self-esteem, engagement in programme, employment, and relationship between client and case manager. Delivery measures may include but not be limited to dates, locations, manner of contact with clients, time spent on categories of duty, and patterns of hospitalising clients.

4. RESULTS

4.1 Identification of eligible papers

There were over 175 studies identified by the search strategy. Eighty-five full text articles were retrieved after excluding studies from the search titles, abstracts and reference lists. Of these full text articles, 57 did not fulfil the inclusion criteria and were excluded; these are not presented, but a list annotated with the reason for exclusion, is available from the authors. A total of 28 articles were eligible for inclusion and were fully appraised, consisting of two papers reporting secondary research (i.e., a systematic review) and 26 papers reporting primary research. These are marked with an asterisk in the **Bibliography**. Other cited publications (e.g., those providing background material), are also presented in the **Bibliography**. Tables summarising articles included in this review have used the terminology and spelling (which differs by country) of the original article.

4.2 Secondary research

The search strategy identified only two relevant systematic reviews. The methods, results and conclusions are described in **Table 7** (p. 20-21).

Davidson et al. (1999) provided a valuable commentary on historical development and potential effectiveness of peer support among individuals with serious mental illness. The review focused on naturally occurring mutual support groups, consumer-run services and employment of consumers as health providers. Most studies included in the review were descriptive, were limited by their small samples and low power and did not have random assignment.

A systematic review produced by the University of Leeds (Simpson and House 2002) considered the evidence involving users in the delivery and evaluation of mental health services. This comprehensive review was based on research published between 1966 and 2001, and included randomised controlled trials and comparative studies. Only five randomised controlled trials were identified with all five meeting specified design criteria. A further seven comparative studies were found. Due to the heterogeneity of the study designs it was not possible to combine these studies using meta-analytic techniques. The authors concluded that mental health service users can be involved as employees, trainers, or researchers without detrimental effect and that involving mental health service users with severe mental disorders in the delivery and evaluation of services is feasible.

Table 7. Involving service users in the delivery and evaluation of mental health services (secondary research, level III-2)

Source	Design, Objective and Methods of Review	Results and Conclusions	Comments
Davidson et al (1999) Yale University School of Medicine Clinical Psychology: Science and practice	This review of non-controlled studies reviewed the historical development and potential effectiveness of peer support among persons with severe mental illness. The three primary modes of peer support included in this review were: 1) naturally occurring mutual support groups, 2) consumer-run services and 3) employment of consumers as providers within mental health services.	<p>This article reviewed six studies on consumer run services. It was suggested that consumer-run services can provide useful services and a constructive peer role-model for those recovering from mental illness. The services tend to have strong minority representations. Service-user run services might be more sensitive to issues of discrimination against people with mental illness and cultural minority background. This article reviewed six studies on consumers as service providers or health professionals. It consistently showed that service-users can adequately provide services to others with serious mental illness. This type of peer support at that time was still relatively new, therefore more rigorous studies are required.</p> <p>The evidence on the effectiveness of naturally occurring mutual support groups remains tentative. They seem to help with social integration among individuals with mental health problems. It was suggested that mutual support groups should focus on supporting mental health treatment, addressing mental health concerns and engage large number of individuals particularly in non-group settings given the low utilisation and high drop out rates.</p> <p>Authors' conclusions Overall, more systematic and prospective studies on peer support is required.</p>	<p>This review did not provide details of how its search was conducted (other than mentioning key word searches of Medline and PsychInfo databases) or whether there were any inclusion or exclusion criteria applied.</p> <p>Feasibility studies were also profiled in the tables of studies on consumer-run services or providers regardless of whether any outcome data was presented in the report.</p>

Table 7. Involving service users in the delivery and evaluation of mental health services (secondary research, level I)

Source	Design, Objective and Methods of Review	Results and Conclusions	Comments
Simpson and House (2002)	This systematic review aimed to identify evidence from comparative studies on the effects of involving users in the delivery and evaluation of mental health services.	Five randomised controlled trials and seven comparative studies were identified. Half of the studies considered involving users in managing cases. Involving users as employees of mental health services led to clients having greater satisfaction with personal circumstances and less hospitalisation.	Involving users in mental health services is generally seen as worthwhile but the effects of involving users have not been thoroughly evaluated, and few attempts to draw conclusions have been made.
University of Leeds, United Kingdom	Databases searched between 1966 – 2001 included Medline, Embase, Cinahl, PsycINFO, HealthSTAR, Cochrane Controlled Trials Register, Web of Science, HMIC, and BIDS using terms (where \$ is wildcard) user\$, consumer\$, client\$, carer\$, caregiver\$, involv\$, participat\$. Medical subject headings (MeSH) included consumer participation, consumer advocacy, patient advocacy, consumer organisations, consumer satisfaction, caregivers, family relations, mental disorders, mental health, mental health services, community mental health centers, and psychiatry.	Authors' conclusions Mental health service users can be involved as employees, trainers, or researchers without detrimental effect and that involving mental health service users with severe mental disorders in the delivery and evaluation of services is feasible.	Despite government policy in the UK strongly supporting the development of involving users in the delivery and evaluation of mental health services, little evidence exists on the effectiveness of such programmes and more formal evaluations are needed.
British Medical Journal	Inclusion criteria Evaluations of the impact of research on services if users had an active role in the design or in collecting the data. Studies about users who delivered services by training mental health professionals. Studies about delivery involving users in partnership with others if services were integrated by health professionals and users working together in a team; cross-consultation; or recruitment, training, supervision, or payment of users by healthcare providers. Exclusion criteria Studies that dealt only with learning disabilities, involvement in decisions about a user's own treatment, providing information to users, user satisfaction surveys researched by the provider (without requiring partnership), general health services not specifically aimed at mentally ill people, forensic services, services for mentally ill people which are not health related; such as housing or vocational rehabilitation, services with no contact with professionals or which could not be run by professionals which operate outside the mental health system; such as self help groups.		

4.3 Primary research

The search identified 26 eligible primary research studies. Six randomised controlled trials (Campbell 2004a, Clark et al. 1999; Klein et al. 1998; O'Donnell et al. 1999; Paulson et al. 1999; Solomon and Draine 1996); seven comparative studies (Chinman et al. 2000; Chinman et al. 2001; Cook et al. 1995; Felton et al. 1995; Lyons et al. 1996; Polowczyk et al. 1993; Segal and Silverman 2002c); and 13 descriptive studies (Bentley 2000; Chamberlin et al. 1996; Hutchison and Pedlar 1999; Meehan et al. 2002; Mowbray et al. 2002; Mowbray and Tan 1993; Petr et al. 2000; Salzer and Shear 2002; Segal et al. 2000; Segal et al. 1997; Tobin et al. 2002; Torrey et al. 1998; Wallcraft 2003) were identified for appraisal from the search strategy.

4.3.1 Study setting

Of the six controlled studies four took place in either a community mental health centre (CMHC) or outpatient style setting and one study was conducted by a non-government/self-help (NGO/SH) provider. One multisite study was conducted across locations and providers. Four of these took place in the USA, one in Canada and one in Australia. All of the comparative studies were conducted in the USA, five in community settings (one mobile team), one with a mixed setting (outpatient, CMHC and NGO/SH) and one that compared participants from CMHC and NGO/SH sector. Ten of the descriptive studies were conducted in NGO/SH setting, two in CMHC or mixed settings and one in an inpatient unit.

4.3.2 Samples

Study samples and the source of recruitment of participants, range of conditions of participants, age, sex, inclusion and exclusion criteria varied from study to study. Refer to tables for clarification and original articles for further detail.

4.3.3 Interventions

A variety of interventions were considered. These included the involvement of current or former users of mental health services as providers in mental health services, for example as case managers in a community mental health service (Solomon and Draine 1996); case managers in an assertive community treatment programme (Paulson et al. 1999); client consumer advocates attached to case management service (O'Donnell et al. 1999); peer counsellors alongside case management service (Klein et al. 1998); peer specialists on case management teams (Felton et al. 1995); case managers in outreach service (Chinman et al. 2000); service providers in community outreach service (Chinman et al. 2001) and users as service providers in mobile crisis assessment service (Lyons et al. 1996). One study looked at current or former users of mental health services as trainers of mental health service providers (Cook et al. 1995).

All studies were published between 1993 and 2004 and these recent publication dates indicate the relatively recent development of this field of enquiry. Consumer-run and consumer-led services are a new dimension of mental health services and most (20 out of 26) of the evaluations to date appear to have been conducted in the USA (76%). Notably, three studies from Australia (12%) have been included, two from Canada (8%) and one from the UK (4%). Of two systematic reviews of controlled or comparative studies identified was one was conducted in the UK and the other in the USA.

No published New Zealand based studies or evaluations were identified from the search strategy used regardless of study design. There may be examples of these within the grey literature but they are unlikely to be studies that have used outcome-based measures of effectiveness.

4.3.4 Outcomes

Studies often used measures of satisfaction developed specifically for the specific study. Only one study actually focuses on the development, reliability and validation of their measure (Segal et al. 2000). Where specifically identified by the research team, details of outcome measures used have been included in the relevant table. Recent studies by Campbell (2004a), Segal et al. (2002b) and O'Donnell et al. (1999) appear to have used a full battery of recognised outcome measures. It is important to note that there is substantial debate over what are appropriate measures to use for the measurement of psychiatric outcomes and this debate is unresolved particularly in the case of outcomes that are relevant to consumers.

4.4 Primary research: study results

Full details of the 26 papers appraised, including source, design, objective and methods, key results and discussion, authors' conclusion and reviewer's comments are provided in **Table 8** (controlled studies, level II) pages 25-30, **Table 9** (comparative studies, level III) pages 31-37 and **Table 10** (descriptive studies, level IV) pages 38-50. Studies are presented alphabetically in reverse chronological order of publication within each table. The authors' conclusions will be summarised in the discussion section of this report, pages 51-58.

Table 8. Brief summary of a range of controlled studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level II)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Campbell (2004a) Overview and preliminary Findings (Research Report)	<p>Primary study, level II; randomized controlled trial, USA</p> <p>This preliminary report provided the rationale, methods, participants baseline characteristics, and selected outcome findings of a bigger randomized controlled study- Consumer-Operated Service Program Multisite Research Initiative (COSP). The experimental conditions consisted of consumer-operated service programs offered as adjunct to traditional mental health services and the control condition consisted of traditional mental health services.</p> <p>This project involved four drop-in centers, two mutual support programs and two educational programs. A total of 1827 participants with severe and persistent mental illness were assessed at baseline, four, eight and twelve months measuring “well-being” (a composite construct reflecting recovery, employment, empowerment, housing, social inclusion, quality of life, meaning of life, hope and life satisfaction). A fidelity assessment tool was developed and used to measure program characteristics and program cost.</p>	<p>The preliminary findings of the 12-month follow-up study were: 1) both experimental and controlled groups showed improved well-being over time; 2) Further analysis indicated that participants randomly assigned to consumer-operated services programs of drop-in centers in addition to traditional mental health services showed greater improvement in well-being over the course of study than participants randomly assigned to only traditional mental health services at those sites. However this preliminary study did not evaluate the degree and timing of participation in the services programs.</p>	<p>Findings support that the participants who were randomized to drop-in centers showed significant improvement in the composite well-being outcome measure (recovery, hope, empowerment, meaning of life, social inclusion, and quality of life). However, to date the intent-to-treat analyses have not found this for mutual support and training and advocacy programs, but the as-treated analyses (when outcomes are examined based on actual attendance) are likely to be much stronger for the mutual support and the training and advocacy services.</p>

Table 8. (Continued) Brief summary of a range of controlled studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level II)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Clark et al. (1999) Psychiatric Services	<p>Randomized controlled trial, Canada.</p> <p>A study at two outpatient facilities compared two methods of collecting data on client satisfaction with mental health services provided by case managers and by physicians. A satisfaction survey instrument was developed with input from clients. A total of 120 clients were randomly assigned to be interviewed by either a staff member or a client. Two methods of data collection were used to collect information on client satisfaction. Two staff interviewers and two client interviewers were hired at each facility. Criteria for selection were the ability to concentrate, ability to probe in a sensitive manner, skill at asking questions, listening skills and the ability to record information. Staff and clients were trained in how to administer the questionnaire through didactic sessions and the use of a videotape. Inter-rater reliability was evaluated using a videotaped session.</p> <p>Thirty clients were assigned to each group, for a total of 120 participants. Clients were interviewed about their satisfaction with case management and physicians services. A new instrument was developed because no standardized satisfaction questionnaire created by clients exists. It was developed using four focus groups comprising of multidisciplinary staff and clients. Clients and staff experts reviewed the questionnaire and determined its face validity. Several pilot interviews were conducted.</p>	<p>The results did not differ between the two facilities. Of the 120 participants, 50 (42%) were female. The two groups were similar across all variables except duration of illness. Clients interviewed by the client interviewers had been ill for a longer period of time than those interviewed by staff members ($p < .02$). The other variables examined were age, number of admissions, gender, marital status, education level and frequency of visitors to the facility. Clients from both facilities reported high levels of satisfaction regardless of the type of interviewer. Clients gave a significantly greater number of extremely negative responses when they were interviewed by client interviewers. The results were the same when chronicity was added as a covariate in the analysis ($p < .022$). No difference between the two groups was found in overall satisfaction with services received from case managers or physicians.</p> <p>Authors' conclusion Clients from both facilities reported high levels of satisfaction regardless of the interviewer but clients give more negative responses when interviewed by clients.</p>	<p>Clients may indeed be very satisfied with services or it is also possible that instruments and data collection methods used are not valid; clients' hesitancy to disclose true thoughts and feelings relates to still depending upon the system for resources and support; social desirability, ie. giving responses they thought would meet with interviewer approval.</p> <p>Hard to generalize second finding due to very small number of client interviewers. However there did appear to be an interviewer effect when clients are very dissatisfied with an aspect of the service.</p> <p>One recommendation arising was that programs should create opportunities for clients to address issues with other clients in privacy: this may allow more valid feedback and be beneficial in increasing clients' involvement in all stages of program evaluation.</p>

Table 8. (Continued) Brief summary of a range of controlled studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level II)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Klein et al. (1998) Research on Social Work Practice	<p>Randomized controlled trial, USA.</p> <p>The aim of this study was to examine a peer social support programme to high risk dually diagnosed clients. The key research question was whether intensive case management (ICM) coupled with peer support (Friends Connection) would provide: a) a more cost effective approach to quality service, and b) significantly affect system outcomes and client integration into the community.</p> <p>A pilot study of 10 randomly selected clients in the study group, and 51 in the comparison group, who had been in community care 1 year prior to this investigation was carried out. Service was provided for a six month period.</p> <p>Data was collected from 61 dually diagnosed clients of a mental health center. Outcomes examined included the number of crisis events (defined as number of petitions for involuntary hospitalisation, emergency room visits, and Mobile Emergency Team contacts, and inpatient hospitalization at the end of the study period. Data from pre- and post-client interviews and case records was also compared. Only 2 individuals in comparison group responded to both pre- and post-client interviews. A consumer member of the team was used to administer both interviews.</p>	<p>The number of crisis events of the comparison group far exceeded that of the study group. Crisis events considered included suicide attempts, disturbances in the place of residence, attacks on staff that necessitated special intervention by agency staff. The number of hospitalizations was dramatically reduced.</p> <p>Clients in the study group reported improved quality of life and perceived their physical and emotional wellbeing as improved over the course of the study.</p> <p>Authors' conclusion Findings suggest that coupling peer social support with intensive case management is associated with positive system outcomes.</p>	<p>Although one of the exclusion criteria for this report was studies focusing on alcohol and drug disorders this study was not excluded as clients clearly experienced severe mental illness and substance use was comorbid (co-occurring).</p> <p>The peer support structures and outcome measures used are relevant for consumers without substance abuse. In addition, this pilot study although small, did use a randomization procedure so is one of the few studies to use a randomized controlled design in this area.</p> <p>Sample size was limited.</p> <p>Many clients refused to participate even in filling out the questionnaire in the pre- and post- intervention stages. Further, only 9 out of the 30 randomly selected clients accepted peer support, whereas 21 indicated disinterest and mistrust.</p> <p>The length of the follow-up was only 6 months, and it is reasonable to assume that a longer follow-up may yield additional gains or even declines in gains.</p> <p>The activity list and the abbreviated quality of life scale devised is not validated psychometrically</p> <p>Self-reporting by clients did not always agree with staff notes, which could indicate biases (by either staff or clients).</p>

Table 8. (Continued) Brief summary of a range of controlled studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level II)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
O'Donnell et al. (1999) Australian and New Zealand Journal of Psychiatry	<p>Randomised controlled trial, Australia.</p> <p>This study investigated the provision of client-focused services to community-based clients with schizophrenia and bipolar disorder. It hypothesised that the delivery of more client-focused services would improve client outcome in terms of functioning, disability and satisfaction with services.</p> <p>Clients referred for case management were randomly allocated to one of three groups: standard case management (n=35), client-focused case management (n=39), or client-focused case management plus consumer advocacy (n=45). Measures of functioning, disability, quality of life, burden of care and service satisfaction were measured at baseline and at 12 months. Outcome data was collected concerning number and duration of hospital readmission, crisis intervention and compliance with treatment and service.</p>	<p>While there were no differences between the groups on quantitative measures of functioning, disability, quality of life, service satisfaction and burden of care, there were significant between-group differences on qualitative measures of satisfaction with services.</p> <p>Authors' conclusions Several methodological difficulties hampered the interpretation of findings. Although clients did not differ on outcome measures of functioning and disability, the group receiving client-focused case management reported greater satisfaction with service delivery.</p>	<p>Client-focused services were developed using an empowerment model of case management and by the addition of consumer advocates. The consumer advocates' role was to encourage the client's self-confidence, provide role models for clients during their recovery, enhance their communication with case managers and participate in recovery agreement meetings if the client wished.</p> <p>Although the Community and Consumer Service (CCS) worked with consumer advocates who were trained by consumer consultants it is not clear whether these advocates were paid members of the staff team. They were always introduced to the client by the case manager.</p> <p>The study was limited by its sample size. This was not related to severity of illness but was generally due to transience and comorbid substance abuse. High attrition rates through the course of the study emphasises the need for very large sample populations to assure representativeness. Selection criteria in this type of study should also be kept broad to be meaningful.</p>

Table 8. (Continued) Brief summary of a range of controlled studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level II)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Paulson et al. (1999) Community Mental Health Journal	<p>Randomized controlled trial, USA.</p> <p>The practice patterns of consumer and non-consumer providers of assertive community treatment are compared using both quantitative and qualitative data collected as part of a randomized trial. This study sought to determine whether the teams differed in the type and amount of time spent on each of tasks performed.</p> <p>The research was conducted at Mind Empowered, Inc (MEI) and assertive case management/supported housing program. MEI was a private, not for profit provider which started as a NIMH funded consumer support program demonstration project to run a drop-in center, and subsequently, case management services. While both consumer and non-consumer teams were administered by MEI, each team was located in separate physical offices to reduce cross "contamination of service activities and clinical styles". Each team consisted of four full-time case managers, and a part-time case manager. Staff members on the consumer team were self-identified mental health consumers with a DSM-III-R diagnosis.</p>	<p>The activity log shows that case managers performed a mix of both direct service and administrative tasks. Overall only minor differences were found in the distribution of time spent on various case manager activities. Both teams spent the majority of time providing support and structure (14% consumer, 15% non-consumer), and coordinating services (8%, 8% respectively). Case managers spent approximately one-third of their time with clients with no difference between teams in the amount of time spent face-to-face or on the telephone. One quarter of the time was spent alone and the remaining time (6%) with family members, staff at other agencies and residential operators.</p> <p>Authors' conclusions Activity log data showed that there were few substantive differences in the pattern of either the administrative or direct service tasks performed by the two teams. In contrast, the qualitative data revealed that there were discernible differences in the "culture" of the two teams. The consumer team "culture" emphasized "being there" with the client while the non-consumer team was more concerned with accomplishing tasks.</p>	<p>Over the life of the project, the majority of the staff had a diagnosis of bipolar disorder (50%); other diagnoses included major depression, schizoaffective disorder and cyclothymia. Staff members on the non-consumer team did not have a diagnosable mental illness.</p> <p>This article discusses in detail some of the boundary issues that arose and how these were interpreted by different teams. It also discusses differences in pace and presence and orientation of the different teams, including the strengths and limitations of their approach.</p> <p>Consumers were more flexible and relaxed in terms of schedule and not as task-oriented, though they still accomplished allocated tasks.</p> <p>Staff turnover and absences were higher on the consumer team while non-consumers were more consistent in the hours they worked throughout project.</p>

Table 8. (Continued) Brief summary of a range of controlled studies retrieved on the effectiveness of consumer-run, consumer-led services for people with mental illness (primary studies, level II)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Solomon and Draine (1996) Research on Social Work and Practice	<p>Randomized controlled trial, USA.</p> <p>This study examined whether a team of mental health consumers delivered intensive case management services differently than a team of non-consumer case managers.</p> <p>Ninety-six seriously mentally ill clients were randomly assigned to consumer and non-consumer teams of case managers. The experimental service was mainly run by mental health service consumers operating as part of a consumer-run advocacy organisation under the auspices of the regional mental health association. Therefore the consumer team had organizational accountability in a recognized non-profit service and advocacy agency in mental health in addition to the principles of a consumer self-help organization. The agency provided a full range of community mental health services in outpatient, day program and residential settings.</p> <p>Teams received the same training, continuing education, and mental health systems support (information systems, compliance with regulations etc). Case management teams were not trained separately, nor were they kept blind to case managers' consumer status. Consumer case managers were given no special consideration in training process. Measures included Quality of Life Interview and Brief Psychiatric Rating Scale (BPRS).</p>	<p>Ninety-one clients stayed in study.</p> <p>Although there were no differences in total service units between teams, the teams differed in terms of location, manner, and with whom the service was delivered. Consumer managers delivered more services face-to-face with the client and fewer services in the office and in interactions with family members and other mental health service providers.</p> <p>Authors' conclusions This study supports the contention that consumers can provide client-centered and service oriented case management services using a service planning and monitoring model. This study did not address whether they could provide a clinical case management model.</p>	<p>In previous analyses of outcomes at one-year, clients were found to be less satisfied with mental health services in general and to have less contact with family than clients served by non-consumer case managers. At two years, however, no differences in outcomes between consumer and non-consumer teams were found. With this mixed result it was thought differences might lie with the delivery of the services.</p> <p>Care was taken to ensure essential differences between the case management teams was that one was composed primarily of consumers within a consumer-operated program whereas the other was not.</p> <p>Definition of consumer status major mental health disorder as per DSM III, at least one prior hospitalization (public or private) and a minimum of 14 days of psychiatric hospitalization, or at least 5 psychiatric emergency service contacts over a 5 year period. To have regular contact in a community mental health service or other outpatient treatment for primary diagnosis of mental illness.</p> <p>Limited numbers of case managers employed at any one time: replication is required for firmer conclusions about consumer case management to be made.</p>

Table 9. Brief summary of a range of comparative studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level III)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Chinman et al. (2001) Community Mental Health Journal	<p>Comparative study, USA. This study describes the Welcome Basket Program (WBP) and reports preliminary outcome data from a pilot study to evaluate its effectiveness.</p> <p>WBP participants who also were receiving outpatient services at the center (the intervention) were compared with a matched sample of people receiving outpatient services at the center only (standard care condition).</p>	<p>92 people received outpatient services at the centre. Of these only 14 (15%) were readmitted to hospital, which was a 50% reduction in re-hospitalizations compared with the general outpatient population. Chi-square analyses revealed no significant differences between the intervention and standard care group on gender, race/ethnicity, diagnosis by condition and mean age.</p> <p>A 2 (WBP versus Standard Care) by 2 (Time 1 versus Time 2) repeated measures ANOVA was conducted on the mean number of readmissions per person and mean number of inpatient days per person. Overall analyses indicate that both groups had fewer admissions at the end of Time 2 than at the end of Time 1 but did not differ significantly from each other at either time. While WBP participants had about 40% more inpatient days than patients in standard care at the end of Time 1, they had 56% fewer inpatient days at the end of Time 2, an overall 75% reduction of inpatient days for WBP participants between Time 1 and 2.</p> <p>Authors' conclusions The data suggests that WBP clients were initially at greater risk for re-hospitalization when compared to those in standard care, and that this intervention shows promise in reducing hospitalization rates among a population at risk.</p>	<p>WBP is an outreach and engagement program developed, staffed and managed entirely by mental health consumers. Consumers designed, evaluated, and operated the WBP from its inception.</p> <p>Random assignment was not used although the groups were matched and found similar on a number of dimensions.</p> <p>Only a limited range of outcomes was reported.</p> <p>Analyses were hampered by skewness of the distributions even with transformations – caused by several participants who had no readmissions or any inpatient days.</p>

Table 9. (Continued) Brief summary of a range of comparative studies retrieved on the effectiveness of consumer-run, consumer-led services for people with mental illness (primary studies, level III)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Chinman et al. (2000) Journal of Nervous and Mental Disease	<p>Comparative study, USA.</p> <p>This study compared the outcomes of services provided by case managers who were mental health system consumers and case managers who were not consumers. The study focused on the first two cohorts that entered the ACCESS program, a 5 year demonstration program.</p> <p>Associations between the type of case manager and clinical outcomes at three time points (baseline, 3 months, and 12 months). A series of one-way repeated measures of analyses of variance were conducted on clients from ACCESS sites that hired consumer providers.</p> <p>Overall sample size for non consumer sites (n=1985), with a mean age=38.52 years; for consumer sites (n=950), with a mean age=38.27 years. Number of users involved not specifically stated. Inclusion criterion was prior psychiatric treatment.</p>	<p>Although there were significant effects of Time for almost every outcome measure (eg. clients improved over time) there were no significant Time x Case Manager interactions. Staff age, race, or gender did not significantly alter the pattern of these results.</p> <p>Authors' conclusions Given that services provided by consumers and non-consumers were associated with equivalent outcomes, the present study showed, using a large sample, the ability of consumers to provide mental health services as members of a case management team.</p>	<p>Difficult to ascertain whether consumer participation or truly consumer-run as no mention of governance role in consumer sites. Author refers to ability of consumers to provide mental health services within a case management team so probably the former.</p> <p>Quasi-experimental design, so it is possible that unmeasured client characteristics may bias the results. Future studies should use random assignment.</p> <p>More clients from consumer sites had diagnoses of drug dependence (p=.000), major depression (p=.000), more psychosis, self-rated and by observer (.000), had less social support (.035) and spent more days homeless (.014). Clients were similar on all other diagnostic categories, gender, race/ethnicity and age.</p> <p>ACCESS project was not specifically designed to assess the effects of the type of case manager services (consumer provided versus non consumer) on client related outcomes. Therefore it is difficult to attribute improvements made by clients served by consumer providers to specific principles of mutual support.</p> <p>Although no differences, further studies are needed of the process of treatment and of the special values of mutual support-based helping relationships. The effectiveness of specific support strategies for consumer providers needs to be assessed as they enter the workforce.</p>

Table 9. (Continued) Brief summary of a range of comparative studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level III)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Cook et al. (1995) Community Mental Health Journal	<p>Comparative study, USA.</p> <p>This project used a randomized design to test the effects of using consumers as trainers for mental health service providers.</p> <p>Fifty-seven mental health professionals (mean age 34.5 years) participated in a two-day training designed to acquaint trainees with the attitudes and knowledge necessary for delivering “assertive case management” services.</p> <p>Participants were randomly assigned to one of two conditions: one in which they received the second day of training from a consumer and the other involving training by a non-consumer. Attitudinal outcome measures were created from a factor analysis of items derived from focus group interviews with consumer service deliverers, using Likert scales. A variety pre-test/post-test instrument was devised from several scales used in prior research.</p>	<p>Analyses revealed that post-training attitudes were significantly more positive for those participants trained by the consumer. Subjective evaluations also reflected positive reactions to the use of consumers as trainers. Even controlling for pre-test attitudes and respondent background characteristics, those in the experimental condition showed more positive post-test attitudes overall, and felt more positively about consumers as service providers and trainers, and expressed more non-stigmatizing attitudes than those trained solely by the non-consumer.</p> <p>Authors’ conclusions The use of a consumer trainer achieved positive results and enhanced the effectiveness of the training. If the goal is to make mental health service delivery training an insightful and integrative experience, this study provides preliminary evidence that this type of approach is viable.</p>	<p>Small sample size so limited power.</p> <p>Results could be simply due to the novelty of having a new trainer on the second day of the curriculum. Possible that any new individual on the second day might achieve better results than the first day trainer. Evaluation comments suggest it was the nature of the trainer as a consumer that led to their unique insights and positive learning experience.</p> <p>Future studies should investigate consumer training using more rigorous designs along with multiple trainers in each condition.</p>

Table 9. (Continued) Brief summary of a range of comparative studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level III)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Felton et al. (1995) Psychiatric Services	<p>Comparative study, USA.</p> <p>This study examined whether employing mental health consumers as peer specialists in an intensive case management program can enhance outcomes for clients with serious mental illness.</p> <p>A quasi-experimental, longitudinal, non-equivalent control group design was used to compare outcomes of clients assigned to three case management conditions: teams of case managers plus peer specialists, teams of case managers plus non-consumer assistants, and case managers only.</p> <p>Outcomes were measured at baseline and at six-month intervals. Repeated measures analysis of variance was used to access between-group differences.</p>	<p>Complete data was available for 104 clients. Compared with clients in the other two groups, clients served by teams with peer specialists demonstrated greater gains in several areas of quality of life and an overall reduction in the number of major life problems experienced. They also reported more frequent contact with their case managers and the largest gains of all three groups in the area of self-image and outlook and social support. For example, clients in the peer specialist group grew more satisfied with their living situations, finances and personal safety than clients in the other groups, which suggests that observed changes in satisfaction reflected not just changes in clients' attitudes but also objective improvements in their life circumstances.</p> <p>No statistically significant differences in outcomes were found between clients served by teams with non-consumer assistants and those served by case managers only. However, effect size comparisons show that clients in the peer specialist group posted the largest gains on 20 of 31 measures.</p> <p>Authors' conclusions Integration of peer specialists into intensive case management programs appears to lead to enhanced quality of life for clients and more effective management.</p>	<p>The use of peer specialists was within the context on an inpatient service so governance and management of this project was under the control of professionals not consumers.</p> <p>There were some sample biases apparent, eg. over-representation in the final sample of clients in the case manager-only condition and of those continuously enrolled in the program. Therefore the findings may not be representative.</p> <p>Results should be interpreted with caution given the study's quasi-experimental design and relatively high attrition.</p>

Table 9. (Continued) Brief summary of a range of comparative studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level III)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments												
Lyons et al. (1996) Community Mental Health Journal	<p>Comparative study, USA.</p> <p>This study investigates consumer service delivery in a mobile assessment program designed to assist homeless people with severe psychiatric disorders.</p> <p>The program was designed to serve people both mentally ill and homeless, on a 16hr basis (originally a 24hr service but changed due to high cost and low night utilization). Staff with prior consumer experience were hired (4 out of 9 staff, one of whom reported periods of homelessness characterised by living in shelters. Of the other five staff, four had outpatient mental health service consumer experience. Two of the four consumer staff were qualified “examiners” which means they had the ability to certify clients for hospitalization.</p> <p>Service data was collected on each open case. These data included basic demographic and clinical characteristics of the clients served and categorizations of the assessed need and service linkages made. Characteristics of service contact (eg. emergency, location, referral source were also documented). Staff worked in pairs (dyads).</p>	<p>Consumer and non-consumer dyads of staff were generally comparable. Results suggested that consumer staff were engaged in more street outreach ($p < .001$) and were less often dispatched for emergencies ($p < .01$). There was a trend for consumer staff to be more likely to certify their clients for psychiatric hospitalization ($p < .05$).</p> <table border="1"> <thead> <tr> <th>Outcome</th> <th>Consumer</th> <th>Non-Consumer</th> </tr> </thead> <tbody> <tr> <td>Hospitalization</td> <td></td> <td></td> </tr> <tr> <td>Voluntary</td> <td>63 (8.6%)</td> <td>72 (10.3%)</td> </tr> <tr> <td>Certification</td> <td>93 (12.7%)</td> <td>65 (9.3%)</td> </tr> </tbody> </table> <p>Certification for hospitalization allowed for transport to nearby hospitals. It is possible, though rare, according to authors, for persons certified to not be admitted. No follow-up data on this was available.</p> <p>Authors' conclusions Consumer staff appear to provide a valuable contribution to this form of service delivery. Mobile assessment staff with personal consumer experience were more likely to do street outreach than were non-consumer staff. This is consistent with the hypothesis that consumer staff are more willing and better able to engage mentally ill people on the street. Several consumer staff chose to communicate their own experiences to the clients they were serving on the street.</p>	Outcome	Consumer	Non-Consumer	Hospitalization			Voluntary	63 (8.6%)	72 (10.3%)	Certification	93 (12.7%)	65 (9.3%)	<p>Not a consumer-run service by strict definition but consumer participation.</p> <p>Comparisons between consumers and non-consumers may be confounded by the definition of consumer used (ie. prior psychiatric hospitalization) as 4 of the 5 “non-consumer” staff had experience of mental illness.</p> <p>Bonferroni correction within variable domains (eg. service delivery variables) were made to allow for the multiple statistical comparisons</p> <p>Assignment of cases was not systematic.</p> <p>A consumer dyad was defined as any pair which included at least one consumer staff member. A non-consumer dyad always had two non-consumer staff.</p>
Outcome	Consumer	Non-Consumer													
Hospitalization															
Voluntary	63 (8.6%)	72 (10.3%)													
Certification	93 (12.7%)	65 (9.3%)													

Table 9. (Continued) Brief summary of a range of comparative studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level III)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Polowczyk et al. (1993) Hospital & Community Psychiatry	<p>Comparative study, USA.</p> <p>Examined the use of consumer interviewers (n=225) and staff interviewers (n=305).</p> <p>Subjects were 530 individuals with serious and persistent mental illness who were attending ten outpatient clinics, three continuing treatment centers, and a psychosocial club. Two groups clinic staff (receptionists not health professionals) and clinic patients administered surveys. First 305 surveyed by staff were randomly selected.</p> <p>The Consumer Satisfaction Questionnaire (CSQ) was used modified by the addition of one question on the extent to which outpatient treatment met individual needs and desires.</p>	<p>Group comparisons revealed no significant differences in age or other demographic characteristics.</p> <p>Patients surveyed by both groups of surveyors reported a high level of satisfaction with outpatient services. The mean satisfaction scores were significantly lower in the patient surveyed group ($p < .05$). However 95% of patients surveyed by staff responded positively compared to 90% of those surveyed by patients.</p> <p>Authors' conclusions Preliminary findings suggest that involving consumers as surveyors in satisfaction studies may produce findings that differs from those in studies with non-professional staff surveyors.</p>	<p>Patient surveyors did not conduct surveys with patients from their own home clinics, whereas all staff surveyors did.</p> <p>Training received was the same. A two day intensive training programme on interviewing, consisting of teaching, role playing and critiques of performance. All procedures were standardized and the training focused on the importance of maintaining a neutral stance.</p>

Table 9. (Continued) Brief summary of a range of comparative studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level III)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments																																																								
Segal et al. (2002) Psychiatric Services	<p>Comparative study, USA.</p> <p>To compare the characteristics and past service use of new enrollees of self-help agencies and community mental health agencies in the same geographical catchment.</p> <p>Interview assessments were conducted with 673 new users at ten pairs of self-help and community mental health agencies serving the same geographical areas. Client characteristics were evaluated with multivariate analyses of variance and chi square tests.</p> <p>Self-help agencies (n=226) and community mental health agencies (n=447). Male 54%.</p>	<p>Clients of community mental health agencies had more acute symptoms, lower levels of social functioning, and more life stressors in the previous 30 days than clients of self-help agencies. The self-help agency cohort evidenced greater self-esteem, locus of control, and hope about the future. Clients of self-help agencies had received more services from facilities other than self-help or community mental health agencies in the last six months, and clients of self-help agencies who were not African American had more long-term mental health service histories. Key: PES Empowerment Scale; HS Hope Scale; RSES Rosenberg Self-Esteem Scale; LCS Locus of Control Scale; HPCS Health Problems Checklist Score; SL Stressful life events in previous month SU; Services used in previous 6 months;</p> <table border="1"> <thead> <tr> <th>Scale</th> <th>Difference</th> <th>(se)</th> <th>p-value</th> </tr> </thead> <tbody> <tr> <td>Psychological functioning</td> <td></td> <td></td> <td></td> </tr> <tr> <td>BPRS</td> <td>-5.21</td> <td>1.01</td> <td><0.001</td> </tr> <tr> <td>CES-D</td> <td>-4.65</td> <td>1.25</td> <td><0.001</td> </tr> <tr> <td>ISFS</td> <td>11.28</td> <td>3.44</td> <td>0.001</td> </tr> <tr> <td>ASFS</td> <td>5.31</td> <td>2.66</td> <td>0.046</td> </tr> <tr> <td>Empowerment/attitude</td> <td></td> <td></td> <td></td> </tr> <tr> <td>PES</td> <td>1.13</td> <td>0.91</td> <td>0.222</td> </tr> <tr> <td>HS</td> <td>-3.28</td> <td>1.2</td> <td>0.006</td> </tr> <tr> <td>RSES</td> <td>2.96</td> <td>0.75</td> <td><0.001</td> </tr> <tr> <td>LCS</td> <td>1.67</td> <td>0.51</td> <td>0.001</td> </tr> <tr> <td>HPCS</td> <td>-0.53</td> <td>0.44</td> <td>0.529</td> </tr> <tr> <td>SL</td> <td>-1.08</td> <td>0.21</td> <td><0.001</td> </tr> <tr> <td>SU</td> <td>1.06</td> <td>0.52</td> <td><0.001</td> </tr> </tbody> </table> <p>Authors' conclusions Community mental health agencies deliver primarily acute treatment-focused services whereas self-help agencies provide services aimed at fostering socialization, mutual support, empowerment, and autonomy.</p>	Scale	Difference	(se)	p-value	Psychological functioning				BPRS	-5.21	1.01	<0.001	CES-D	-4.65	1.25	<0.001	ISFS	11.28	3.44	0.001	ASFS	5.31	2.66	0.046	Empowerment/attitude				PES	1.13	0.91	0.222	HS	-3.28	1.2	0.006	RSES	2.96	0.75	<0.001	LCS	1.67	0.51	0.001	HPCS	-0.53	0.44	0.529	SL	-1.08	0.21	<0.001	SU	1.06	0.52	<0.001	<p>Self-help agency was defined as an organisation with a client director, a governing board with a majority of client members, and an organizational structure in which clients hire and fire staff, including employed professionals. Self-help agencies provided client-operated services guided by a self-help ideology. Community mental health agencies were county mental health organizations.</p> <p>This is a well-conducted quantitative study, which utilized good research methods and incorporated validated measures of psychological disability and other outcome measures. For example, the BPRS Brief Psychiatric Rating Scale, the CES-D Centers for Epidemiological Studies Depression Scale, the ISFA Independent Social Functioning Scale and the ASFS Assisted Social Functioning Scale.</p>
Scale	Difference	(se)	p-value																																																								
Psychological functioning																																																											
BPRS	-5.21	1.01	<0.001																																																								
CES-D	-4.65	1.25	<0.001																																																								
ISFS	11.28	3.44	0.001																																																								
ASFS	5.31	2.66	0.046																																																								
Empowerment/attitude																																																											
PES	1.13	0.91	0.222																																																								
HS	-3.28	1.2	0.006																																																								
RSES	2.96	0.75	<0.001																																																								
LCS	1.67	0.51	0.001																																																								
HPCS	-0.53	0.44	0.529																																																								
SL	-1.08	0.21	<0.001																																																								
SU	1.06	0.52	<0.001																																																								

Table 10. Brief summary of a range of descriptive studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level IV)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Bently (2000) Psychiatric Rehabilitation Journal	<p>Descriptive study, USA.</p> <p>To plan, implement and evaluate a series of educational and skills training sessions run in conjunction with a peer-run drop in center.</p> <p>Each session was evaluated by every participant using an evaluation form that assessed the participant's perceptions of the instructor and content.</p>	<p>Of the 15 participants across all six sessions:</p> <p>Post-session 77% strongly agreed that the instructor cared about their learning and personal development; 50% strongly agreed that the instructor tried to connect the workshop content to their daily experience; 83% strongly agreed that they encouraged discussion and questions; 60% strongly agreed that they had increased their skills; 67% strongly agreed that they had learned things they could actually use.</p> <p>Six month follow-up Material on communication skills was the most frequently used content from the empowerment training; also counselling skills and content on building self-esteem were appreciated.</p> <p>Authors' conclusions The "Empowering our Own" training is a successful case example of one model for the use of helping ideas and skills to assist leaders of drop-in centers move toward mastery in their peer-run organizations and recovery in their personal lives.</p>	<p>Small sample size (n=10) of those who attended more than one session.</p> <p>Attempted to look at outcomes in relation to perception of training but no specific measures or scales used to assess effectiveness of training.</p> <p>Most participants were primarily interested in the training for personal improvement and only secondarily for use in their consumer-run organizations.</p> <p>Very preliminary evaluation of training programme.</p>

Table 10. (Continued) Brief summary of a range of descriptive studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level IV)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Chamberlin et al. (1996) Psychiatric Rehabilitation Journal	<p>Descriptive study, USA.</p> <p>Six self-help programmes were surveyed to increase understanding about the users of such programs, their demographics, their perceptions of how such programs have affected the quality of their lives.</p> <p>Participatory action research model.</p> <p>Ten-person consumer advisory board designed, planned study and developed survey questions. A list of potential national self-help programs was developed and initial recruitment letters sent out to request participation. Six programs were selected that were thought to represent the broad scope of consumer self-help programs.</p> <p>Instruments for measurement were developed by the board and focused on quality of life, self-esteem and social supports. All ratings were based on self-report. A separate instrument was developed to obtain descriptive information (mission, structure, activities and physical facilities) about the programs themselves. Instruments were pilot tested with a local self-help program not included in the study. Data collection took six months and yielded 271 questionnaires. Response rates ranged from 10 to 55%.</p>	<p>Descriptive data was synthesised. From keyword analysis of mission statements programs focus on empowerment, independence, promote choice, self-determination, provide peer support, education, advocacy and assistance to access services. Program budgets ranged from US\$47000 to US\$2.9 million per year. Staff ranged from 1.5 to 12.5 plus significant numbers of volunteers to supplement paid staff. Other characteristics of the program were described.</p> <p>Difference among self-help programs on the major measures: Quality of life $F=6.8$, $p<0.001$ Satisfaction with program $F=1.67$, $p=0.14$ Community activities $F=2.58$, $p=0.03$ Self-esteem $F=2.37$, $p=0.04$ Service utilization $F=1.29$, $p=0.27$ Social supports $F=2.65$, $p=0.023$</p> <p>Authors' conclusions Respondents indicated that being involved in self-help has a salutary effect on their quality of life, including general life satisfaction.</p>	<p>Limited financial resources to conduct the study.</p> <p>Programmes had to be run by consumers who had control of their own budget, staff, and activities (n=64).</p> <p>Questions were developed from existing scales but standardised, psychological instruments were avoided as it was felt that these might be threatening to members.</p> <p>Selection and sampling bias may be a problem in this study and also only six of 64 programs that agreed to participate were included in study. Unlikely to be representative survey of self-help members</p> <p>Not able to systematically track response rates</p> <p>Prospective, longitudinal design required to see if self-help positively affects hospitalization and other outcomes.</p>

Table 10. (Continued) Brief summary of a range of descriptive studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level IV)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Hutchison and Pedlar (1999) Canadian Journal of Community Mental Health	<p>Descriptive study, Canada.</p> <p>National survey of Independent Living Centres (ILCs).</p> <p>Describes what are ILCs; what are their impact; and what implications do they have for mental health reform?</p> <p>Study directly examined three questions; firstly are the centres helpful in overcoming obstacles experienced by people with disabilities; secondly how effective are ILCs as mediating structures between IL paradigm and beliefs, values and expectations of the community; and finally how do the specific programmes and services offered by ILCs contribute to their impact?</p> <p>Three IL sites were selected based on the fact that the centre was long-standing (over 5 years old) and well established, the centre had a relatively strong funding base and the centre had key core IL components in place. In year one qualitative individual (n=18, but only 5 were consumers) and focus-group interviews (18 groups, 70 people) were carried out. In year two, a quantitative survey was conducted (n=111 returned out of 211, response rate of 52.6%).</p> <p>A 5-point Likert scale was used for survey questions (1 – not at all, 2 – a little, 3 – somewhat, 4 – a lot, 5 – totally), mean (SD).</p>	<p>ILCs were found to treat people with disabilities as valued and fully contributing members of the community. Study participants report that this is significantly different from the sort of treatment which people experience elsewhere in the community, where they are seen as clients/disabled persons.</p> <p>Empowerment: Impact on self-esteem 3.74 (0.83) Gain knowledge/awareness 3.74 (0.73) Gaining control over life 3.71 (0.79) Strengthen social networks 3.65 (0.82) Contribute to community 3.62 (0.85) Building new skills 3.50 (0.91)</p> <p>Promote philosophy Independence/self-direction 4.00 (0.79)</p> <p>Factors contributing to perceived weaknesses in ILCs ability to foster community change Lack of funding 3.29 (1.18) Limited programmes 2.64 (1.14)</p> <p>Authors' conclusions Closer affiliation between ILCs and the mental health field would offer consumers another "promising practice" of relevance to the empowerment process.</p>	<p>The guiding principles of the community-based and consumer-driven centres include espousing an empowerment philosophy which incorporates consumer control/self-direction over decision making; offering cross-disability support; providing options and choice, flexibility and freedom; and promoting inclusion and full participation.</p> <p>Core programmes and functions of the ILCs enable local centres to offer information and referral, individual advocacy and consultation, peer support, and research and development.</p> <p>Cross disability focus that includes people with experience of the mental health system. People with non-physical disabilities were concerned with opportunities available to them.</p>

Table 10. (Continued) Brief summary of a range of descriptive studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level IV)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Meehan et al. (2002) International Journal of Mental Health Nursing	<p>Descriptive study, Australia.</p> <p>Aim: to evaluate the impact of a 16-week training program in peer support.</p> <p>Consumer peer support trainees were recruited from the community through a newspaper advertisement. Selection criteria included: self-identification as a mental health consumer; a stated interest in helping others interpersonally; and a willingness to develop skills in peer support and advocacy. Of 10 participants selected, most were female (n=8), aged 21-60 years. The training program was developed by a committee of service providers, teaching staff and consumer representatives. The goal was to prepare former consumers of mental health services to provide peer support to current inpatients. Data was collected via a focus group and a number of measures including the Perceived Stress Scale, the Spielberger Anxiety Inventory, the Rosenberg Self-Esteem Scale and the Locus of Control Scale.</p>	<p>Focus group discussions</p> <p>Generally satisfied with format and content. Opportunity to interact with staff and patients was appreciated but sometimes difficult. Lack of clear job description created some problems for participants at ward level.</p> <p>Scale data</p> <p>Changes in scores were assessed using a repeated measures analysis of variance (ANOVA). State anxiety (ie. anxiety at the present moment) was at its highest during the first four weeks of program but decreased steadily as trainees became familiar with their role in the hospital; trait anxiety (anxiety one generally experiences) was also elevated at the beginning of the program but decreased over the duration. Stress levels were outside normal range on first day but decreased to within a normal range over 4 weeks, High initial locus of control scores (indicates a perception that outcomes are within the control of the powerful rather than oneself) decreased as course progressed. As a group trainees had below average self-esteem scores that climbed to normal levels as the course progressed. While participants demonstrated improvement on all measures employed, the changes obtained did not reach significance at p=0.05.</p> <p>Authors' conclusions</p> <p>This study highlighted need for training and skill development for former patients wishing to participate in mental health service delivery. Well organised training, clearly defined roles, code of conduct for consumer workers will further facilitate the introduction of consumer participation. Expressions of commitment must be followed by action in the form of financial support, recognition of consumer involvement, promotion of ongoing education for consumer service providers and development of policies that consider and value consumer participation.</p>	<p>No evidence to suggest psychological wellbeing of trainees suffered as a result of interacting with patients in the hospital – in fact the opposite was the case.</p> <p>This study was not strictly on a consumer-run organisation but the study demonstrates the feasibility of evaluating training programmes designed and implemented by consumers.</p> <p>One of only a few Australasian studies.</p> <p>Strength of this descriptive study is that it attempted to use some validated quantitative measures to monitor the impact of the program on the psychological wellbeing of the participants.</p>

Table 10. (Continued) Brief summary of a range of descriptive studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level IV)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Mowbray et al. (2002) Health and Social Work	<p>Descriptive study, USA.</p> <p>This study examined the operations, services and structure of 32 consumer drop-in centers and the difference between consumer-run and consumer-involved programs. It also examined the extent to which the consumer drop-in centers served targeted beneficiaries, how they were structured, whether their services and activities were provided as intended and to what extent these characteristics varied according to whether the drop-in center was controlled and run by consumers or only involved consumers as staff or advisors.</p> <p>Thirty-two of 33 drop-in centers (in Michigan) participated in a one-hour telephone survey, representing a response rate of 97%. The survey was developed by a group of consumer representatives who provided input on the survey's content and methods. Nine areas were identified (1) the center's history, (2) its structure; its governing body, including size and number of consumers, (3) its operations, (4) services contracted and provided, (5) staffing and resources, (6) activities of staff, (7) the micro-context, (8) the macro context, and (9) challenges the center faced.</p>	<p>Results indicated that centers operate in many ways like other human services businesses, albeit with much smaller budgets. Funding levels, salaries and services showed great heterogeneity among centers and in comparison with reports in the literature. Centers autonomously run by consumers and centers with consumer-involvement (operated by a non-consumer agency) were found to differ significantly on several variables including consumer control, funding and service levels.</p> <p>Authors' conclusions There is a need for more comprehensive investigation, using onsite observations and surveys, to obtain consumer opinions about why they come to the centers. Establishing an operational model that accurately reflects how consumer-operated services are supposed to operate is a necessary step in eventually investigating the effectiveness of such programs.</p>	<p>A major dimension of the framework for organising consumer roles as providers is the extent to which the service is actually controlled by consumers. Thus, consumer-run services reflect a goal of formal service provision controlled by consumers themselves.</p> <p>The authors note that although the desire is to assess the effectiveness of consumer-operated services, according to standard evaluation practice, descriptive and process, studies are needed to document how consumer-run programs operate, what they do, and the mechanisms through which they affect consumer outcomes.</p> <p>Small sample size though large compared to other studies.</p>

Table 10. (Continued) Brief summary of a range of descriptive studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level IV)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Mowbray and Tan (1993) Journal of Mental Health Administration	<p>Descriptive study, USA.</p> <p>Describes development and operation of demonstration projects designed to implement an innovative service model (the consumer-run drop in center).</p> <p>Examined the extent to which “centers” met programmatic expectations, collecting retrospective satisfaction and impact assessments from participants and compared differences in operation across six centers.</p> <p>Data collection was through interviews with drop-in center participants (n=120). Two-day site visits were scheduled at each center. Target number of interviews per center was 20. An attempt was made to interview all members who were present on the interview days. Consent was obtained and the refusal rate was 7%.</p> <p>Used the Group Environment Scale Form (GESF).</p>	<p>Male 62%, Age range 17-69 years, mean age 36.7 years. Previously hospitalised for mental health reasons (82%), used mental health services at some time (91%), never used formal mental health services (9%).</p> <p>High levels of satisfaction were found as well as participants feeling they actually ran the centers. Consumer ratings varied across the centres, but satisfaction didn't relate to attributes of a center's physical environment. Problems were identified concerning relationships with the mental health treatment system in some locations, funding levels, and full participation of some subgroups of consumers.</p> <p>Authors' conclusions In interpreting results of evaluation, mental health professionals and policy makers should keep in mind that what a consumer-operated center becomes is largely determined by the mental health consumers. This is what a consumer-operated center is about, one run by consumers for consumers. Policymakers can facilitate and ensure the continuing operation and the success of such services by providing material resources and support.</p>	<p>These centers were truly consumer-run, with consumers in all staff and volunteer positions. The governing body was wholly made up of consumers.</p> <p>Funding levels were typically inadequate and most issues were with inadequate resources.</p> <p>Effectiveness was only indirectly assessed.</p> <p>Mowbray and Tan (1992) appears to use data from the same study. The chronologically later report provides more analytical details.</p> <p>Limitations in sampling may compromise whether sample is representative of center's beneficiaries, maybe select sample is biased in favour of center. No comparison or control groups were used.</p>

Table 10. (Continued) Brief summary of a range of descriptive studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level IV)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Petr et al. (2000) Psychiatric Rehabilitation Journal	<p>Descriptive study, USA.</p> <p>Exploratory study looking at the need, activities, structure and purposes of a consumer-run organization (CRO) for youth. Aimed to establish whether there was a need for a self-help and CRO for youths and its feasibility.</p> <p>Key informants were interviewed (Kansa). Telephone, small group, and in person interviews (n=23); mental health providers (n=6) and CRO members (n=8); family-run organisation, parents and staff (n=4); and other young people accessing services (n=5).</p>	<p>At the time of publication, there was no group or organisation that focused solely on young people with emotional and behavioural disorders.</p> <p>Critical needs identified by youth included desire for friendships with peers, age-related peer activities, and the availability of peer support in the form of drop-in centres. Respondents suggested any CRO needed to be a separate entity from adult CROs but some affiliation with community mental health centers. A youth CRO would require some level of adult facilitation but young people would need to feel a strong sense of ownership through establishing and enforcing the rules, organising activities and maybe even paying dues.</p> <p>Authors' conclusions The creation of CROs will require overcoming three major implementation hurdles: sponsorship, funding and leadership. Because young people themselves lack the prerequisite knowledge and skills, leadership will need to come from families and mental health professionals working together with them.</p>	<p>No details of sample selection criteria: mostly a sample of convenience.</p> <p>No specific measures or scales were used to assess the effectiveness of the existing services included in this study which may or may not have had a focus on youth.</p>

Table 10. (Continued) Brief summary of a range of descriptive studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level IV)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Salzer and Shear (2002) Psychiatric Rehabilitation Journal	<p>Descriptive study, USA.</p> <p>Aimed to systematically examine consumer-provider benefits. A qualitative study of a peer-support program for persons with recurring mental health and substance use disorders was conducted. A wide-ranging semi-structured interview was developed to inquire about the peer support specialists' (PSS) experience with their position. Looked at the extent to which PSS benefit from their positions.</p> <p>Fourteen PSS, 6 women and 8 men were interviewed. The PSS ranged in age from 30 to 59 years (mean 42 years). Nine of the 14 had some experience working in the human service field. The same interviewer conducted all the interviews. Consent was obtained and 13 of 14 interviews were taped and transcribed. Statements were reviewed to develop thematic categories. These were reviewed to derive meta-themes.</p>	<p>Twenty-nine thematic categories were reported that reflected what they had liked or benefited from as a PSS. Perceived benefits reported included: Facilitating others recovery and interpersonal competence (helping others in their recovery, giving back to others, helping people in the community, rewarding to watch people get better, helping others grow and change, building long-term relationships with consumers).</p> <p>Social approval (feel appreciated, important, self esteem); professional growth (building skills, gain experience, knowledge); job related (independence, travel, challenging, fun, job flexibility).</p> <p>Other aspects less important were facilitating own recovery, getting paid for what "I'd do anyway", and mutual support.</p> <p>Authors' conclusions Research and policy implications include that attention should be paid to understanding the helper-therapy principle. There needs to be assessment of consumer-provider outcomes as part of research on consumer-delivered services (CDS). Cost-benefit analyses should also be conducted. CDS also provide valuable employment opportunities for people with psychiatric problems.</p>	<p>This study did not analyse any outcome data but did describe the perceived benefits of being a peer support specialist in detail.</p> <p>It did focus on a community-based consumer-run service. The specific program assessed is called the Friends Connections, a peer-support program.</p> <p>Qualitative methodology used and the measures taken to ensure its reliability were discussed in more detail by these authors (compared with other articles).</p>

Table 10. (Continued) Brief summary of a range of descriptive studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level IV)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Segal et al. (2000) Psychiatric Services	<p>Descriptive study, USA.</p> <p>This study examined the development of a scale that assesses clients' satisfaction with services and their involvement in treatment decisions.</p> <p>Long-term users of four client-operated mental health self-help agencies were interviewed at baseline (n=310) and six months (n=248) using the 11-item Self-Help Agency Satisfaction Scale (SHASS). The scale was developed on the basis of consumers' input about their satisfaction with services and their involvement in treatment decisions. To explore the relationship between satisfaction as measured by the SHASS and outcomes, the six-month interview included four outcome measures – independent and assisted social functioning, symptom severity, and a sense of personal empowerment. Internal consistency, stability and discriminant validity were evaluated.</p> <p>A total of 321 baseline interviews were initiated and 310 completed (97%). A total of 248 participants completed six-month interviews (80%). No participant who could be located refused a follow-up interview. Mean age was 38 ± 8.44 years.</p>	<p>Factor analyses confirmed that the SHASS has two subscales, one assessing satisfaction with involvement in treatment decisions. The scale and its subscales showed high internal consistency, moderate stability, and discriminant validity. The SHASS subscales showed modest associations with two of four outcome measures – assisted and independent social functioning.</p> <p>Authors' conclusions The SHASS is a brief instrument that can be used to measure clients' satisfaction with their involvement in treatment in mental health self-help agencies.</p>	<p>Although the focus of this study is on the reliability and validity of the SHASS scale rather than the effectiveness of services evaluated, it has been included in the tables because of its direct relevance to other studies of effectiveness conducted by the same author.</p>

Table 10. (Continued) Brief summary of a range of descriptive studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level IV)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Segal et al. (1997) Journal of Mental Health Administration	<p>Descriptive study, USA.</p> <p>National survey of consumer-run agency heads (n=189) and self-help agency (SHA) consumers (n=310).</p> <p>To see if consumer perceptions of service approximate to those of leaders and if SHA and Community Mental Health (CMHA) consumers differ in program perceptions.</p> <p>Three comparison samples sent to 430 organisations; 189 (44%) returned. Of these 179 identified themselves as SHAs.</p> <p>Used Community-Oriented Program Environment Scale (COPES). 100-item true-false instrument. Each item is a statement about the structural, process, or interpersonal relationships within the service program.</p>	<p>Prior to gathering study data, all COPES items were reviewed first by researchers and consumers. Items not relevant were eliminated. Remaining items were weighted to add to a total score of 10. Cluster analysis was used to determine relationships between subscales.</p> <p>SHA reality conformed to ideology in offering opportunities for consumers to experience involvement, support and autonomy in the receipt of the needed service.</p> <p>Authors' conclusions While showing only modest differences from CMHAs on relationship and treatment characteristics, SHA consumers differ in their perceived control over program rules (previously shown to be important in promoting positive outcomes).</p>	<p>SHA was defined as having one of three criteria: no professional members; if professionals were involved, consumers had the power to dismiss them; and the organisation was consumer-directed.</p> <p>Limitations include that samples very heterogeneous, one region was over-represented. Differences in the timing of SHA and CMHA studies could account for differences in CMHA and SHA membership samples.</p> <p>This study did not provide any strong measures of outcomes for consumers so is not informative about the effectiveness of CRCL services.</p>

Table 10. (Continued) Brief summary of a descriptive study retrieved on the effectiveness of service user-run or service user-led services, for people with mental illness (primary studies, level IV)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Tobin et al. (2002) Australian Health Review	<p>Descriptive study (survey), Australia.</p> <p>The aim of this project was to evaluate the level, extent and quality of consumer participation, and to examine whether there were demonstrable differences between services with different resource commitments.</p> <p>The project was managed by a steering committee that comprised the programme director, two researchers, one clinician consumer advocate (psychiatrist), full-time salaried consumer coordinator and four consumers nominated by consultative committees.</p> <p>Face-to-face interviews were conducted with consumers by consumers. A semi-structured questionnaire was used that examined consumer perceptions of level of participation, encouragement to participate in their own treatment, in service development activities, and in consumer-initiated projects.</p>	<p>A census of all users of inpatient/outpatient services, day programs, community teams, consumer consultative committees and consumer-led activities at particular points in time over a 2 week period. Acutely unwell consumers (on the day) were excluded as well as those requiring acute crisis team interventions. A cohort of 122 consumers was identified and asked to participate. Of these 43% (n=52) agreed to participate. Of these 31% withdrew prior to interview (n=16) leaving a total of 36 consumers who completed the interview.</p> <p>Findings identified low familiarity and involvement with the concept of consumer participation. Barriers to involvement included lack of motivation or invitation, stigma and a lack of information. A need to integrate consumer participation activities into the wider system.</p> <p>Authors' conclusion Devoting energy and resources to consumer initiatives (and thereby ensuring a politically correct approach) may not be a worthwhile exercise. Such initiatives need to be based on evidence, available resources and identifiable and achievable outcomes, with a balance struck between endorsing the value of consumer participation and establishing realistic goals for what can be offered and managed.</p>	<p>Although not looking at a consumer-run service this study outlines a research project managed by a steering group consisting primarily of consumers and implemented by consumer researchers/ interviewers.</p> <p>A high rate of refusal and withdrawal may limit the generalisability of this study.</p> <p>Reasons for non-participation included lack of time, side effects of medication, unstable illness, other commitments, and lack of interest in or knowledge of the area.</p>

Table 10. (Continued) Brief summary of a range of descriptive studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level IV)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Torrey et al. (1998) Psychiatric Rehabilitation Journal	<p>Descriptive study, USA.</p> <p>To describe the potential role for consumer-run services.</p> <p>Three community mental health centers (CMHC) that had converted from day treatment to supported employment were interviewed along with local consumer leaders.</p>	<p>All CMHC leaders had a similar long-term vision for meeting the social needs of consumers. That in time, consumer-run services would develop to offer social opportunities to consumers and that the CMHC role would be limited to teaching consumers social skills, and linking consumers to integrated community-based, social offerings.</p> <p>Early experiences CMHCs struggled to facilitate the development of consumer services. Leaders had to decide whether to provide social activities run by professionals.</p> <p>Later experiences Factors associated with active, well attended, consumer-run services included dynamic consumer leadership, state financial support, and technical and political support from the state and the CMHC. Consumers believe that a key to the success of the service had been its focus on supporting recovery: the service encouraged and supported individuals to move ahead in their lives.</p> <p>Authors' conclusions Recovery oriented consumer-run services, when developed, can offer significant social benefits. Relating to others who have suffered similar painful experiences is a critical element in the recovery of many consumers. CMHC staff members with the inherent constraints of their professional roles cannot match the social opportunity and deep human connectedness that consumers can offer each other.</p>	<p>No details provided of questions asked or sampling frame.</p> <p>No specific measures or scales used to assess the effectiveness of services included in this study.</p> <p>This study did not specifically investigate consumer-run services but they appear to have developed as a consequence of this type of evaluation and analysis.</p> <p>Consumer-run services are now a separate corporation from the CMHC, reporting to their own board of directors.</p>

Table 10. (Continued) Brief summary of a range of descriptive studies retrieved on the effectiveness of service user-run or service user-led services for people with mental illness (primary studies, level IV)

Source	Design, Objective and Methods of Study	Results and Discussion	Comments
Wallcraft (2003) Health Service Journal	<p>Descriptive study, UK.</p> <p>To determine views on how user-involvement should be conducted. To explore how well existing mechanisms work. To determine how user-involvement could be more effective.</p> <p>A postal survey of 318 of 896 validated mental health user-led groups. Face-to-face interviews, project visits and focus groups with 25 local groups and 30 national movement activists. All researchers had personal experience of mental illness.</p>	<p>Although most groups take part in local consultation, most are so poorly funded they are not in a position to carry out this work. A high proportion had insufficient resources to employ even one full-time worker. Hard to support members involved in committee or to consult or provide feedback to members. Budgets, spent mostly on communication, newsletters, postage, and telephone, mostly conducted by unpaid volunteers. Overreliance on volunteers.</p> <p>Responses revealed frustration about a lack of real input, use of volunteers, lack of payment and burn-out of activists.</p> <p>Authors' conclusions Based on interviews and observations, it appears that user involvement is making a difference, but its role has been described by some users as 'influence without power'.</p>	<p>Capacity building is very important for user groups.</p> <p>Service user issues may be on the agenda but at the bottom of a very long list of priorities and competing with national policy guidance.</p> <p>Very little information about the groups sampled and their characteristics.</p> <p>No specific outcome measures or scales to assess effectiveness.</p>

5. DISCUSSION

5.1 Summary of evidence

This report systematically reviewed the international evidence relating to the effectiveness of service user-run or service user-led mental health services for people with mental illness.

Approximately 175 articles were identified by the search strategy. From 85 articles identified as potentially eligible for inclusion, a final group of 28 papers was selected for appraisal, including 26 primary research studies and two systematic reviews. The main results are presented in the sections 5.5.1 to 5.1.3.

Most research in the field of mental health actively draws upon three major types of studies: true experiments, quasi-experiments, and case-control designs. True experiment is a generic term applied to studies with an intervention or experimental manipulation and random assignment of subjects to conditions. When true experiments are conducted in the context of an intervention, they are referred to as a randomised controlled trial (RCT).

From the standpoint of demonstrating the impact of a particular variable of interest, true experiments permit the strongest basis for drawing inferences. Sometimes it is not possible to control all features that characterise true experiments as some facets of a study, such as assignment of participants to conditions, or of conditions within the setting, cannot be randomised.

Quasi-experiment refers to those designs in which the conditions of true experiments are approximated. These can also provide a relatively strong basis for assessing influences (Kazdin 2003).

Mowbray and Tan (1993) have suggested that, given the limited level of knowledge in regard to self-help and consumer-operated programmes, it is more than appropriate to also use non-controlled study designs. The more recent review by Simpson and House (2002) only considered controlled or comparative study designs as controlled studies, more specifically randomised controlled trials are considered the gold standard for evaluating effectiveness. However Chen (1990) asserts that evaluators should first address whether programmes are serving their targeted beneficiaries, with service delivery activities and programmes 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. For this reason, descriptive studies are also included in this review. The following three sections summarise the literature appraised.

5.1.1 Descriptive studies

Bently and colleagues undertook a preliminary evaluation of training programmes on a small sample (n=10) of those who attended more than one session of training. They attempted to look at outcomes in relation to the training but no specific measures or scales were used to assess the effectiveness of the training. Most participants were primarily interested in the training for personal improvement and, only secondarily, for use in their service user-run organisations (Bentley 2000).

Six self-help programmes were surveyed to increase understanding about users of such programmes, their demographics, their perceptions of how such programmes have affected the quality of their lives. Respondents indicated that being involved in self-help had a positive effect on their quality of life, including general life satisfaction (Chamberlin et al. 1996).

Hutchison and Pedlar (1999) examined "Independent Living Centres" in Canada. The core programmes and functions of these local centres enable consumers to offer information and referrals, individual advocacy and consultation, peer support, and research and development. Their affiliation with the mental health field was somewhat tenuous.

The study by Meehan et al. (2002) highlights the need for training and skill development for former service users wishing to participate in mental health service delivery. Their project evaluated the impact of a 16-week training programme in peer support. Well-organised training,

clearly defined roles, codes of conduct for service user workers will further facilitate the introduction of consumer participation. Expressions of commitment must be followed by action in the form of financial support, recognition of service user involvement, promotion of ongoing education for consumer service providers and the development of policies that consider and value service user participation.

Mowbray et al. (2002) examined the operations, services and structure of 32 consumer drop-in centres and the difference between service user-run and service user-involved programs. Although there is an urgent need to assess the effectiveness of consumer-operated services, according to standard evaluation practice, parallel descriptive and process studies are also needed to document how service user-run programs operate, what they do, and the mechanisms through which they affect consumer outcomes.

An earlier study by the same author, one of the first on these types of service user initiative, describes the development and operation of demonstration projects designed to implement a consumer-oriented service model, the consumer-run drop-in centre (Mowbray and Tan 1993). High levels of satisfaction were found as well as participants feeling they actually ran the centres. Problems were identified concerning relationships with the mental health treatment system in some locations, funding levels, and full participation of some subgroups of service users.

Petr et al. (2000) conducted an exploratory study looking at the need, activities, structure and purposes of a service user-run organisation for young people. They concluded that the creation of these primarily requires sponsorship, funding and leadership. In addition, because young people lack some of the prerequisite knowledge and skills, leadership may need to come from families and mental health professionals working together with the young people.

A qualitative study of a peer-support programme for persons with recurring mental health and substance use disorders by Salzer and Shear (2002) found that perceived consumer-provider benefits described included developing interpersonal competence (by helping others in their recovery and giving back to others), a sense of helping people in the community, helping others grow and change, and building long-term relationships with other service users.

A study by Segal et al. (2000) looked at the development of a scale that assesses clients' satisfaction with services and their involvement in treatment decisions. Long-term users of four client-operated mental health self-help agencies were interviewed at baseline and at six months. The Self-Help Agency Satisfaction Scale (SHASS) is a brief instrument that can be used to measure clients' satisfaction with their involvement in treatment in mental health self-help agencies and the scale and its subscales showed high internal consistency, moderate stability, and discriminant validity. Segal et al. (1997) also conducted a national survey of service user-run agency heads and self-help agency consumers. Self-help organisations offered opportunities for service users to experience involvement, support and autonomy in the receipt of services.

Tobin et al. (2002) evaluated the level, extent and quality of consumer participation in an Australian service, examining whether there were differences between services with different resources. They found there was low familiarity and involvement with the concept of consumer participation. Barriers to involvement included lack of motivation or invitation, stigma and a lack of information. They suggested a need to integrate service user participation activities into the wider system.

Three community mental health centres that had converted from day treatment to supported employment and local consumer leaders were interviewed. Factors associated with active, well-attended, service user-run services included dynamic consumer leadership, state financial support, and technical and political support from the state (USA) and the community mental health centre. The authors conclude that recovery-oriented service user-run services, when developed, can offer significant social benefits. Relating to others who have suffered similar painful experiences is a critical element in the recovery of many service users. Community mental health centre staff members with the inherent constraints of their

professional roles cannot match the social opportunity and deep human connectedness that consumers can offer each other (Torrey et al. 1998).

Wallcraft (2003) surveyed a large number of mental health user-led groups in the UK. Responses revealed frustration about a lack of real input, over reliance on the use of volunteers, lack of payment and burn-out of activists.

These studies were all descriptive. They are low in the hierarchy of evidence (indicative of methodological rigour), however given the dearth of research in this area they are nonetheless very important in indicating the potential for service development and service evaluation in this domain.

5.1.2 Comparative studies

Chinman et al. (2001) describe the Welcome Basket Program and reports preliminary outcome data from a pilot study to evaluate its effectiveness. Participants who also were receiving outpatient services at the centre (the intervention) were compared with a matched sample of people receiving outpatient services at the centre (standard care condition). Findings from this study suggest that the Welcome Basket Program participants were initially at greater risk for re-hospitalisation when compared to those in standard care, and that this intervention may help reduce hospitalisation rates among this at risk population.

A comparative study by Chinman et al. (2000) looked at the outcomes of services provided by case managers who are mental health system service users and case managers who were not service users. Given that services provided by consumers and non-consumers were associated with equivalent outcomes, the present study showed, using a large sample, the ability of service users to provide mental health services as members of a case management team.

Felton et al. (1995) examined whether employing mental health consumers as peer specialists in an intensive case management programme can enhance outcomes for clients with serious mental illness. Compared with clients in the other two groups, clients served by teams with peer specialists demonstrated greater gains in several areas of quality of life and an overall reduction in the number of major life problems experienced. They also reported more frequent contact with their case managers and the largest gains of all three groups in the area of self-image and outlook and social support. The authors reported that integration of peer specialists into intensive case management programmes appears to lead to enhanced quality of life for clients and possibly more effective management.

Lyons et al. (1996) investigated consumer service delivery in a mobile assessment programme designed to assist homeless people with severe psychiatric disorders. Service user staff appear to provide a valuable contribution to this form of service delivery. Mobile assessment staff with personal consumer experience were more likely to do street outreach than were non-service user staff. This is consistent with the hypothesis that service user staff are more willing and better able to engage with mentally ill people on the street.

A study by Polowczyk et al. (1993) compared the use of consumer interviewers (and staff interviewers). Their preliminary findings suggest that, although training received was the same, involving service users as surveyors in satisfaction studies may produce findings that differ from those in studies with non-professional staff surveyors.

Segal et al. (2002) contrast the characteristics and past service use of new enrollees of self-help agencies and community mental health agencies in the same region. Significant differences in psychological functioning and empowerment/attitudes were observed. They suggest that although self-help and community mental health agencies both deliver primarily acute treatment-focused services, a critical difference is that self-help agencies appear to provide services aimed more at fostering socialisation, mutual support, empowerment, and autonomy.

Of the seven comparative studies included, one additional new study was identified (Segal et al. 2002a) and one study was excluded (Wood and Wilson-Barnett 1999) from our review compared with the Simpson and House (2002) review.

5.1.3 Controlled studies

Campbell and her colleagues (2004a) conducted a multi-site randomised controlled research program (COSP) involving 1827 participants with severe and persistent mental illness in the United States. This controlled study addressed a number of methodological limitations of previous investigations by ensuring good sample size, multiple locations covering a range of mental health facilities such as drop-in centers and educational/advocacy/mutual support programs, the application of the most stringent test of treatment effectiveness (the use of a study design that incorporated random allocation and a control group), development of a recovery-oriented outcome measures and a fidelity test to make sure the service-led programs do what they claim to do. The initial findings are very promising. Participants in the experimental conditions consisting of service-users led programmes offered as adjunct to traditional mental health services showed greater improvement in well-being than participants in the control condition consisting of traditional mental health services only.

Clark et al. (1999) compared two methods of collecting data on client satisfaction with mental health services provided by case managers and by physicians. A satisfaction survey instrument was developed with input from clients. No difference between the two groups was found in overall satisfaction with services received from case managers or physicians. Clients from both facilities reported high levels of satisfaction regardless of the interviewer but clients give more negative responses when interviewed by clients.

A randomised controlled trial by Klein et al. (1998) examined a peer social support programme for high risk, dually diagnosed clients. Findings suggested that coupling peer social support with intensive case management was associated with more positive system outcomes. The number of crisis events of the comparison group far exceeded that of the intervention group by the end of the study. Furthermore the number of hospitalisations was dramatically reduced. Clients in the study group also reported improved quality of life and perceived their physical and emotional wellbeing as improved over the course of the study.

Only one published controlled study was found from Australia. O'Donnell et al. (1999) investigated the provision of client-focused services to community-based clients with schizophrenia and bipolar disorder. Clients referred for case management were randomly allocated to one of three groups: standard case management, client-focused case management or client-focused case management plus consumer advocacy. While there were no differences between the groups on quantitative measures of functioning, disability, quality of life, service satisfaction and burden of care, there were significant between-group differences on qualitative measures of satisfaction with services. The group receiving client-focused case management reported greater satisfaction with service delivery.

The practice patterns of service user and non-service user providers of assertive community treatment were compared using both quantitative and qualitative data collected as part of a randomised trial. The study by Paulson et al. (1999) sought to determine whether the teams differed in the type and amount of time spent on each of tasks performed. Activity log data showed that there were few substantive differences in the pattern of either the administrative or direct service tasks performed by the two teams. In contrast, the qualitative data revealed that there were discernable differences in the "culture" of the two teams. The service user team "culture" emphasised "being there" with the client while the non-service user team was more concerned with accomplishing tasks.

Solomon and Draine (1996) examined whether a team of mental health consumers delivered intensive case management services differently from a team of non-consumer case managers. The findings from their study support the contention that service users can provide client-centred and service oriented case management services using a service planning and monitoring model. However this study did not address whether consumers could effectively also provide a clinical case management model.

Most of the controlled studies identified in this review focused on consumer participation services where the emphasis was on alternative models of "case management". Consumers

in these studies were working primarily within traditional mental health services but were not necessarily employed in services where consumers were the majority in leadership roles or retained overall governance. One study focused on using consumers as interviewers in service evaluation. The COSP study is clearly the most comprehensive study to date. The strength of these studies is that they all used random assignment to groups and they used a control group. Sample size, with the exception of COSP, however, was often small and a high attrition rate through the course of the study or low initial response rates emphasise the need for very large sample populations to assure representativeness of these types of studies.

5.2 Limitations of the review

The review scope was developed with the assistance of Mental Health Commission which specified the scope of the report and decided to exclude services concerned primarily with addiction. It was confined to an examination of the effectiveness of the service or programme and did not consider the acceptability, or any ethical, economic or legal considerations associated with these services or programmes. Only one researcher (CD) appraised the articles included in this review; however the second author (ST) had copies of all studies and assisted in reviewing the critique performed by the first author.

This study has used a structured approach to review the literature. There are some inherent limitations with this approach which are discussed. Namely, systematic reviews are limited by the quality of the studies included in the review and the review's methodology.

This review has also been limited by the restriction to English language studies. Restriction by language may result in study bias, but the direction of this bias cannot be determined. In addition, the review has been limited to the published academic literature, and has not appraised unpublished work with the exception of the preliminary results from the multisite COSP study. These results are in the public domain but further published findings are pending. Restriction to the published literature is likely to lead to bias since the unpublished literature tends to consist of studies not identifying a significant result and important studies in this area may be less likely to reach publication or appear in unpublished newsletters or periodicals. Reports published as book chapters were also not included. Qualitative research studies were not included in the present review as they are not designed to investigate the effectiveness of services for people with mental disorders. Some of the excluded studies were cited in this review to explain what service user-run or service user-led services are and highlight some of the relevant issues. The qualitative research identified is useful in providing a rich description of how the service user-run services were delivered, the experience and perceptions of service providers and consumers, and the specific context of individual programmes. They give indications about the value of service user-run services in helping individuals recovering from mental disorder. Although a number of descriptive studies were included in the range of programmes examined, for this level of evidence this review should be considered selective rather than exhaustive. The authors are aware that a variety of other informative, descriptive studies that contribute to the emerging research base for peer-run support programs also exist and have may not been specifically profiled in this review, for example, studies outlined in a summary by Campbell (2004b) and in the book edited by Clay (2005).

Papers published pre-1980 were not considered as this is a relatively new area of research, most studies identified by the search were conducted in the 1990's or more recently. This approach is consistent with the only other systematic review to examine this area (Simpson and House 2002).

The review was limited to studies describing consumer partnership services and service user-run or operated services. Mutual support and training and advocacy programmes were not specifically considered. The scope of this report was expanded to include consumer partnership services because so few non-descriptive studies (that include good data on outcomes) have been conducted and published to date. Studies on consumer partnership services are relevant to the future development of service user-run or operated services and the consumer workforce in New Zealand.

The majority of the published articles on the topic were written by professionals with or without input from consumers which might have influence on how the study was designed and

what outcomes were measured. In turn, results reported in those studies might not reflect or capture consumers experience in service user-run or operated services.

The studies were initially selected by examining the abstracts of these articles. Therefore it is possible that some studies were inappropriately excluded prior to examination of the full text article. Where detail was lacking or ambiguous, papers were retrieved as full text to minimise this possibility.

All of the studies included in this review were conducted outside New Zealand and, therefore, their generalisability to the New Zealand population and context may be limited and needs to be considered. The New Zealand context needs to take into account the Treaty of Waitangi and multiculturalism, as well as the uniqueness of our public mental health system and the role that mental health service users have in it. Although two studies took place in Australia, both were of consumer participation (O'Donnell et al. 1999; O'Donnell et al. 1998; Tobin et al. 2002) and only the O'Donnell study used a control group. O'Donnell et al. (1998) described the development of the advocacy programme and the difficulties encountered by the project. One New Zealand-based study that was excluded from this review has looked at the attitudes of professionals to consumer involvement (Kent and Read 1998). They reported that while most professionals view the concept positively, progress may be occurring faster at the level of individual treatment than at the organisational level. Professionals with a more biological (as opposed to psychosocial) orientation were less likely to predict that services would improve if consumers were involved in the planning of services or were employed therein. The authors of this study made a number of recommendations, including the need for the value of a collaborative approach to be more emphasised in professional training programmes. All the studies included in this review were from English-speaking countries and none of the studies mentioned needing to provide translation or interpretation for participants who spoke English as a second language. Therefore the results from the present review do not provide any evidence of effectiveness that reflects service user-run services for newly arrived immigrants from non-English speaking background. Secondly, even though the published literature clearly documents that indigenous people are overrepresented in both the mental health e.g., (Commission 2004; Kvernmo and Heyerdahl 2003; Vicary and Andrews 2001) and justice systems, to date little attention has been paid to involving people from indigenous populations in evaluations of consumer services. Therefore the findings that emerge from the present review may have limited relevance to indigenous peoples' mental health.

Research on service user-run or led services is a relatively new area which creates a different set of limitations. The evidence presented in this report is limited in that much of the research has been driven predominately by professionals, for instance, the majority of services provided (five out of the six studies) graded as level II evidence (randomised controlled trials) were operated by mental health professionals and the service-user run or led services were somehow "attached" to the mainstream services. Outcome measures adopted by these studies may not be consistent with consumers' experiences. For example, increased levels of "hope" may be seen as an important outcome by consumers (Copeland and Mead 2004) but this has not been included as an outcome measure in any of the studies included in this review. Any studies on service user-run services will benefit tremendously from greater level of input from service users from the early stage of research design right up to the data collection and analysis. Future consumer services and/or initiatives should have research and evaluation costs ringmarked and built in to their project plans and budgets reflecting strategic imperatives that have been outlined previously (Ministry of Health 2002)

The literature searches, article retrieval, appraisal of studies and writing of this review were conducted over a limited timeframe (October, 2003 to September, 2004).

This review has greatly benefited from the comments provided by Shery Mead, USA as well as by Debbie Peterson, Mental Health Foundation of New Zealand but it has not been exposed to wider peer review.

For a detailed description of interventions and evaluation methods, and results used in the studies appraised, the reader is referred to the original papers cited.

5.3 Directions for future research

Further research initiatives should address limitations and gaps in knowledge identified by this review. More work describing the models of consumer run services and further development of instruments to measure programme fidelity and service user outcomes may be required before meaningful effectiveness research can proceed.

5.3.1 Key international research

A large study completed in the United States has attempted to address the issue of small sample size (ie. in most studies the power to detect an effect is compromised by the small number of participants in both the intervention and control groups). The Consumer-Operated Service Program Multi-site research initiative was run in eight states Connecticut, California, Florida, Illinois, Maine, Missouri, Pennsylvania and Tennessee. Seven research sites (California and Florida are partnered as one site) investigated the effectiveness of consumer-operated services compared with traditional mental health services. Study investigators asked questions such as “what is a consumer-operated program (COSP)? Does a consumer-operated service offer benefits not available from a traditional service alone? How is it different from a traditional mental health service?” The subjects of this research project were clients of traditional mental health services, some of whom were randomly assigned to the consumer-operated programmes. All of these participants were interviewed using a common protocol developed jointly by the seven sites.¹

5.3.2 New Zealand research

The potential currently exists for New Zealand-based research and evaluation on service user-run, service user-led services. For example, there is a range of service user-run, service user-led groups (voluntary and funded) already active at a national and regional level, among these is the Manuka Steering Group that is seeking to form a national collective, with current participation from the Regional Consumer Networks, NAMHSCA (National Association of Mental Health Services Consumer Advisors), and Balance NZ - Bipolar and Depression Network and other representatives of the grass roots consumer movement in New Zealand. Balance NZ recently conducted a national evaluation (comparative study) of a peer-run training programme which was delivered in four locations by Mary Ellen Copeland. This project had received ethical approval from relevant committees.

A variety of “boutique” consumer services also exist around the country though many are underresourced to provide their core services let alone conduct robust evaluation of what they do. A list of New Zealand based groups is provided in **Appendix One**.

What is distinctive about these groups is their commitment to identifying and responding to local needs as perceived by local service users, service user organisations and service user leaders. The projects are based on the ideas of consumers themselves. The provision of support is based primarily on models of self-help and incorporating values of self-determination, empowerment, peer support and personal productivity.

¹ Jean Campbell (campbellj@mimh.edu) was the principal investigator for the COSP study and preliminary results from this study from the intent-to-treat analyses are included in this review but the as-treated analyses are yet to be reported. In May 2005 in a personal communication to the Mental Health Commission she reported that the final analyses are complete and reports on these findings are being prepared.

6. CONCLUSIONS

This report systematically reviewed the evidence for the effectiveness of service user-run or service user-led mental health services for people with mental illness. There is a mixed record of research on consumer delivered services. Despite a great deal of prior descriptive work that supports the feasibility of service user provided services only a limited number of controlled studies have been published that focus on outcomes for people who receive services from service users.

Overall, research on consumer services reports very positive outcomes for clients. This review of effectiveness found some studies that reported higher levels of satisfaction with services, general wellbeing and quality of life while others reported no significant differences between service user-run services and mental health services run by non-service user providers. No studies reported evidence of harm to service users or that consumer services were less effective than the equivalent services offered within a traditional setting.

The evidence base supporting the effectiveness of service user-run services is gradually expanding. The findings to date have to be interpreted with caution as the majority of service user-run services identified by this review were operated alongside clinical staff, peer specialists on case management teams or crisis teams. This implies that the setting in which studies were conducted fulfils the definition of a consumer provided or partnership service but may not meet the more stringent operational definition of a consumer run service in terms of the level of autonomy, self-governance and the level of consumer control required. The positive effect on outcomes could potentially be greater for consumer run services than those with a participation model of consumer involvement. This is as yet unknown. Therefore it is vitally important that in the future effectiveness research measuring meaningful outcomes for service users is carried out on a wider range of different models or types of services in existence and that any differences in effect are formally evaluated. Consumer-run services worldwide receive very limited funding from mental health budgets despite a growing trend that suggests they may represent an effective model of mental health service delivery. Furthermore, to justify their place in the array of services offered within the mental health sector, a strong case can be made that services should only be required to demonstrate equivalent effectiveness compared with traditional services rather than superiority in regard to outcomes for clients.

This review also confirms that very little evaluative work has been done in this area in New Zealand. There are a number of explanations as to why no studies of effectiveness have been conducted in New Zealand. Firstly, service user-run or led services are a relatively new development in New Zealand; therefore they have not drawn much attention from researchers. New Zealand services may also still be at the early stage of trying to articulate the feasibility, style (including how) and the type of services being delivered. Secondly, research money in mental health is extremely competitive and research on service user-run services may not be seen as priority by external funders. The third reason relates to the limited development of consumers' research and workforce capacity New Zealand in general. Although several documents have alluded to the need for developing the service user workforce (Health Funding Authority 2000; Mental Health Commission 2004; Mental Health Commission 1998; Ministry of Health 1990), investment to date has been scant.

Solomon and Draine (2001) suggest that research resources need to be focused less on service user-provided services as adjunctive to professional services and more on determining the effectiveness of stand-alone consumer-provided services in order to develop evidence to influence policy decisions. It is important that as part of this process consumers are integrally involved in the design and selection of outcomes measures that will be meaningful and consistent with the philosophy and values embodied by service user-run services.

What a service user-run, service user-led service becomes is basically determined by the consumers. This is what it is about, a service run by consumers, for consumers. What others such as policy makers, funders and planners can do is to facilitate and ensure the continuing operation of such services through material resources and support (Mowbray and Tan 1993). Ultimately it is the mental health service users themselves, members and staff, who create the service and make it work.

BIBLIOGRAPHY

* studies included in systematic review

Alperovitch, S. (2002). The consumer movement in mental health care. *Israel Journal of Psychiatry & Related Sciences*, 39, 159-164.

Barlow, S. H., Burlingame, G. M., Nebeker, R. S., & Anderson, E. (2000). Meta-analysis of medical self-help groups. *International Journal of Group Psychotherapy*, 50, 53-69.

*Bentley, K. J. (2000). Empowering Our Own: peer leadership training for a drop-in center. *Psychiatric Rehabilitation Journal*, 24, 174-8.

Descriptive study examining training initiatives implemented in conjunction with peer-run drop in centre. Level IV.

Berger, E., Carter, A., Casey, D., & Litchfield, L. (1996). Consumer note. What's happening with consumer participation? *Australian & New Zealand Journal of Mental Health Nursing*, 5, 131-135.

*Campbell, J. (2004a). Consumer-Operated Services Program (COSP) Multisite Research Initiative: Overview and Preliminary Findings: Missouri Institute of Mental Health, University of Missouri School of Medicine.

Further information available from <http://www.cstprogram.org/consumer%20op/index.html>.

Randomised controlled trial. Level II.

Campbell, J. (2004b). Emerging Research Base of Peer-Run Support Programs. Missouri Institute of Mental Health. Personal communication to Sonja Goldsack Mental Health Commission, 4 May 2005.

Carlson, L. S., Rapp, C. A., & McDiarmid, D. (2001). Hiring consumer-providers: barriers and alternative solutions. *Community Mental Health Journal*, 37, 199-213.

Chamberlin, J. (1977). On our own: Patient-controlled alternatives to the mental health system. England: MIND.

*Chamberlin, J., Rogers, E. S., & Ellison, M. L. (1996). Self-help programs: A description of their characteristics and their members. *Psychiatric Rehabilitation Journal*, 19, 33-42.

Descriptive study. Survey of self-help programmes and satisfaction with user-run programmes. Level IV.

*Chinman, M. J., Rosenheck, R., Lam, J. A., & Davidson, L. (2000). Comparing consumer and nonconsumer provided case management services for homeless persons with serious mental illness. *Journal of Nervous and Mental Disease*, 188, 446-453.

Descriptive/Quasi-experimental study. Level III-2.

*Chinman, M. J., Weingarten, R., Stayner, D., & Davidson, L. (2001). Chronicity reconsidered: improving person-environment fit through a consumer-run service. *Community Mental Health Journal*, 37, 215-29.

Comparative (pilot) study. Some descriptive outcome data reported. Level III.

Chinman, M., Kloos, B., O'Connell, M., & Davidson, L. (2002). Service providers' views of psychiatric mutual support groups. *Journal of Community Psychology*, 30, 349-366.

*Clark, C. C., Scott, E. A., Boydell, K. M., & Goering, P. (1999). Effects of client interviewers on client-reported satisfaction with mental health services. *Psychiatric Services*, 50, 961-3.

Randomised controlled trial. No effectiveness outcome data reported on consumer-run service but on consumer interviewers in evaluating mental health services. Level II.

Clay, S., Schell, B., Corrigan, P. W., & Ralph, R. O. (2005). *On Our Own Together: Peer Programs for People with Mental Illness*. USA: Vanderbilt University Press.

*Cook, J. A., Jonikas, J. A., & Razzano, L. (1995). A randomized evaluation of consumer versus nonconsumer training of state mental health service providers. *Community Mental Health Journal*, 31, 229-38.

Comparative/Quasi-experimental study (partial randomisation). Level III-2.

Connor, H. (1999). Collaboration or chaos: a consumer perspective. *Australian & New Zealand Journal of Mental Health Nursing*, 8, 79-85.

Copeland, M., & Mead S. (2004). *Wellness Recovery Action Plan and Peer Support*. 1st edition: Peach Press.

Corrigan, P. W., & Garman, A. N. (1997). Considerations for research on consumer empowerment and psychosocial interventions. *Psychiatric Services*, 48, 347-352.

Corrigan, P. W., Calabrese, J. D., Diwan, S. E., Keogh, C. B., Keck, L., & Mussey, C. (2002). Some recovery processes in mutual-help groups for persons with mental illness; I: qualitative analysis of program materials and testimonies. *Community Mental Health Journal*, 38, 287-301.

*Davidson, L., Chinman, M., Kloos, B., Weingarten, R., Stayner, D., & Tebes, J. K. (1999). Peer support among individuals with severe mental illness: A review of the evidence. *Clinical Psychology-Science and Practice*, 6, 165-187.

Systematic review of non-controlled trials. Level III-2.

Dixon, L., Krauss, N., & Lehman, A. (1994). Consumers as service providers: the promise and challenge. *Community Mental Health Journal*, 30, 615-625; discussion 627-634.

Dougherty, R. H. (2003). Consumer-directed healthcare: the next trend? *Behavioral Healthcare Tomorrow*, 12, 21-27.

Emerick, R. E. (1991). The Politics of Psychiatric Self-Help - Political Factions, Interactional Support, and Group Longevity in a Social-Movement. *Social Science & Medicine*, 32, 1121-1128.

*Felton, C. J., Stastny, P., Shern, D. L., Blanch, A., Donahue, S. A., Knight, E., et al. (1995). Consumers as peer specialists on intensive case management teams: impact on client outcomes. *Psychiatric Services*, 46, 1037-44.

Comparative/Quasi-experimental study with longitudinal, nonequivalent control group. Level III-2.

Finch, A. E., Lambert, M. J., Brown, G., Bentley, K. J., Petr, C. G., Holtquist, S., et al. (2000). Attacking anxiety: a naturalistic study of a multimedia self-help program. *Journal of Clinical Psychology*, 56, 11-21.

Genovich-Richards, J., & Wyzkiewicz, J. V. (2002). Quality toolbox. Consumers: from perceptions to participation. *Journal for Healthcare Quality*, 24, 39-41.

Happell, B., Pinikahana, J., & Roper, C. (2002). Attitudes of postgraduate nursing students towards consumer participation in mental health services and the role of the consumer academic. *International Journal of Mental Health Nursing*, 11, 240-250.

Health Funding Authority (2000). Tuutahitia te wero, meeting the challenges. Mental Health Workforce Development Plan 2000-2005. Christchurch: Health Funding Authority.

Hodges, J. Q., & Segal, S. P. (2002). Goal advancement among mental health self-help agency members. *Psychiatric Rehabilitation Journal*, 26, 78-85.

Hopton, J., & Nolan, P. (2003). Involving users in mental health services. *Mental Health Practice*, 6, 14-18.

*Hutchison, P., & Pedlar, A. (1999). Independent living centres: an innovation with mental health implications? *Canadian Journal of Community Mental Health*, 18, 21-32.

Descriptive study. Level IV.

Kaufmann, C. L., Ward-Colasante, C., & Farmer, J. (1993). Development and evaluation of drop-in centers operated by mental health consumers. *Hospital & Community Psychiatry*, 44, 675-678.

Kazdin, A. (2003). *Research Design in Clinical Psychology*. Boston: Allyn and Bacon.

Kent, H., & Read, J. (1998). Measuring consumer participation in mental health services: are attitudes related to professional orientation? *International Journal of Social Psychiatry*, 44, 295-310.

*Klein, A. R., Cnaan, R. A., & Whitecraft, J. (1998). Significance of peer social support with dually diagnosed clients: Findings from a pilot study. *Research on Social Work Practice*, 8, 529-551.

Randomised controlled trial of dually diagnosed consumers. Looks at effectiveness of peer social support programme. Level II.

Kvernmo, S., & Heyerdahl, S. (2003). Acculturation strategies and ethnic identity as predictors of behavior problems in Arctic minority adolescents. *Journal of the American Academy of Child & Adolescent Psychiatry*, 42, 57-65.

Lammers, J., & Happell, B. (2003). Consumer participation in mental health services: looking from a consumer perspective. *Journal of Psychiatric & Mental Health Nursing*, 10, 385-392.

Linhorst, D. M., & Eckert, A. (2002). Involving people with severe mental illness in evaluation and performance improvement. *Evaluation & the Health Professions*, 25, 284-301.

Linhorst, D. M., & Eckert, A. (2003). Conditions for empowering people with severe mental illness. *Social Service Review*, 77, 279-305.

Lovell, K., Richards, D. A., & Bower, P. (2003). Improving access to primary mental health care: uncontrolled evaluation of a pilot self-help clinic. *British Journal of General Practice*, 53, 133-135.

*Lyons, J. S., Cook, J. A., Ruth, A. R., Karver, M., & Slagg, N. B. (1996). Service delivery using consumer staff in a mobile crisis assessment program. *Community Mental Health Journal*, 32, 33-40.

Comparative study of consumer staff in service delivery. Does not meet strict criteria of consumer-run service. Level III-2.

MacNeil, C., & Abbott, K. (2000). An Evaluation of the Peer Specialist Initiative: The Bureau of Recipient Affairs at the New York State Office of Mental Health.

Marrone, J. (1994). If everybody is doing it, how come it doesn't get done? Consumer-directed and consumer-run service delivery. *Psychiatric Rehabilitation Journal*, 18, 131-134.

Mawhinney, S., & McDaid, C. (1997). 'Having your say': self-advocacy and individuals experiencing mental ill-health ... including commentary by Meyer J. *Nursing Times Research*, 2, 380-390.

McLean, A. (1995). Empowerment and the psychiatric consumer/ex-patient movement in the United States: contradictions, crisis and change. *Social Science & Medicine*, 40, 1053-1071.

Mead, S., Hilton, D., & Curtis, L. (2001). Peer support: a theoretical perspective. *Psychiatric Rehabilitation Journal*, 25, 134-141.

*Meehan, T., Bergen, H., Coveney, C., & Thornton, R. (2002). Development and evaluation of a training program in peer support for former consumers. *International Journal of Mental Health Nursing*, 11, 34-9.

Descriptive study (Australasian). Level IV.

Mental Health Commission. (1998). Blueprint for Mental Health Services in New Zealand: How things need to be. Wellington: Mental Health Commission.

Mental Health Commission. (2002). Service user participation in mental health services: a discussion document. Wellington, New Zealand: Mental Health Commission.

Mental Health Commission (2004). Report and progress 2002-2003, towards implementing the Blueprint for mental health services in New Zealand. Wellington: Mental Health Commission.

Miller, L. (1997). ANGELS, Inc. a consumer-run supported employment agency. *Psychiatric Rehabilitation Journal*, 21, 160-163.

Minett, R. J. (2002). User participation in mental health care: a literature review. *British Journal of Therapy & Rehabilitation*, 9, 52-55.

Ministry of Health. (1990). Developing the Mental Health Workforce, Report of the National Mental Health Workforce Development Committee. Wellington: Ministry of Health.

Ministry of Health (2002). Mental Health (Alcohol and Other Drugs) Workforce Development Framework. Wellington: Ministry of Health.

*Mowbray, C. T., & Tan, C. (1992). Evaluation of an innovative consumer-run service model: the drop-in center. *Innovations & Research*, 1, 19-24.²

Descriptive study (face-to-face interviews). Level IV.

*Mowbray, C. T., & Tan, C. (1993). Consumer-operated drop-in centers: evaluation of operations and impact. *Journal of Mental Health Administration*, 20, 8-19.

Descriptive study (face-to-face interviews). There were few differences across centres. Level IV.

Mowbray, C. T., Moxley, D. P., Thrasher, S., Bybee, D., McCrohan, N., Harris, S., et al. (1996). Consumers as community support providers: Issues created by role innovation. *Community Mental Health Journal*, 32, 47-67.

² Appears to use the same data on outcomes reported in previous study Mowbray and Tan (1992).

Mowbray, C. T., Moxley, D. P., Jasper, C. A., & Howell, L. L. (1997). Consumers as providers in psychiatric rehabilitation. Columbia, USA.: International Association of Psychosocial Rehabilitation Services.

Mowbray, C. T., Moxley, D. P., & Collins, M. E. (1998). Consumers as mental health providers: first-person accounts of benefits and limitations. *Journal of Behavioral Health Services & Research*, 25, 397-411.

*Mowbray, C. T., Robinson, E. A., & Holter, M. C. (2002). Consumer drop-in centers: operations, services, and consumer involvement. *Health & Social Work*, 27, 248-61.

Descriptive study (telephone survey). Centres autonomously run by consumers and centres with consumer involvement (run by a non-consumer agency) were found to differ significantly on several variables. Level IV.

Mueser, K., Glynn, S., Corrigan, P., & Baber, W. (1996). A Survey of Preferred Terms for Users of Mental Health Services. *Psychiatric Services*, 47, 760-761.

National Health and Medical Research Council. (2000). How to use the evidence: assessment and application of scientific evidence. Canberra: NHMRC.

Nikkel, R. E., Smith, G., & Edwards, D. (1992). A consumer-operated case management project. *Hospital & Community Psychiatry*, 43, 577-579.

O'Donnell, M., Proberts, M., & Parker, G. (1998). Development of a consumer advocacy program. *Australian & New Zealand Journal of Psychiatry*, 32(6), 873-879.

*O'Donnell, M., Parker, G., Proberts, M., Matthews, R., Fisher, D., Johnson, B., et al. (1999). A study of client-focused case management and consumer advocacy: the Community and Consumer Service Project. *Australian & New Zealand Journal of Psychiatry*, 33, 684-93.

Randomised controlled trial. Good study design with random allocation to one of three groups. Previously validated outcome measures utilised but no effectiveness data on clearly defined consumer-run service although one of the intervention groups included client-focused case management plus adjunctive consumer advocacy, ie. consumer participation service. Level II.

O'Hagan (2000). Realising Recovery through the Education of Mental Health Workers: Recovery-based Competencies and Resources for New Zealand. Mental Health Commission, Wellington, New Zealand.

*Paulson, R., Henrickx, H., Demmler, J., Clarke, G., Cutler, D., & Birecree, E. (1999). Comparing practice patterns of consumer and non-consumer mental health service providers. *Community Mental Health Journal*, 35, 251-69.

Randomised controlled trial. Level II.

Peck, E., Gulliver, P., & Towel, D. (2002). Information, consultation or control: user involvement in mental health services in England at the turn of the century. *Journal of Mental Health*, 11, 441-451.

Perron, B. (2002). Online support for caregivers of people with a mental illness. *Psychiatric Rehabilitation Journal*, 26, 70-77.

*Petr, C. G., Holtquist, S., & Martin, J. S. (2000). Consumer-run organizations for youth. *Psychiatric Rehabilitation Journal*, 24, 142-148.

Descriptive study. Level IV.

Pilgrim, D., & Waldron, L. (1998). User involvement in mental health service development: how far can it go? *Journal of Mental Health, 7*, 95-104.

Polowczyk, D., Brutus, M., Orvieto, A., Vidal, J., & Cipriani, D. (1993). Comparison of Patient and Staff Surveys of Consumer Satisfaction. *Hospital & Community Psychiatry, 44*, 589-591.

Powell, T. J., Yeaton, W., Hill, E. M., & Silk, K. R. (2001). Predictors of psychosocial outcomes for patients with mood disorders: The effects of self-help group participation. *Psychiatric Rehabilitation Journal, 25*, 3-11.

Pudlinski, C. (2001). Contrary themes on three peer-run warm lines. *Psychiatric Rehabilitation Journal, 24*, 397-400.

Richards, D. A., Lovell, K., & McEvoy, P. (2003). Access and effectiveness in psychological therapies: self-help as a routine health technology. *Health & Social Care in the Community, 11*, 175-182.

Robert, G., Hardacre, J., Locock, L., Bate, P., & Glasby, J. (2003). Redesigning mental health services: lessons on user involvement from the Mental Health Collaborative. *Health Expectations, 6*, 60-71.

Rogers, S. (1998). To work or not to work: that is not the question. *Journal of Psychosocial Nursing & Mental Health Services, 36*, 42-46.

Rowland, R. R., Gilliland, C., & Moxley, D. P. (1993). A consumer-initiated job search training program. *Journal of Rehabilitation, 59*, 61-6.

Salzer, M. S., Rappaport, J., & Segre, L. (1999). Professional appraisal of professionally led and self-help groups. *American Journal of Orthopsychiatry, 69*, 536-540.

*Salzer, M. S., & Shear, S. L. (2002). Identifying consumer-provider benefits in evaluations of consumer-delivered services. *Psychiatric Rehabilitation Journal, 25*, 281-8.

Descriptive study. Level IV.

Schwartz, C. E., & Sendor, R. M. (1999). Helping others helps oneself: response shift effects in peer support. *Social Science & Medicine, 48*, 1563-1575.

Segal, S. P., Silverman, C., & Temkin, T. (1995). Measuring empowerment in client-run self-help agencies. *Community Mental Health Journal, 31*, 215-227.

*Segal, S. P., Silverman, C., & Temkin, T. (1997). Program environments of self-help agencies for persons with mental disabilities. *Journal of Mental Health Administration, 24*, 456-464.

Descriptive study of self-help association leaders and participants. Level IV.

*Segal, S. P., Redman, D., & Silverman, C. (2000). Measuring clients' satisfaction with self-help agencies. *Psychiatric Services, 51*, 1148-52.

Descriptive study (face-to-face interviews). Level IV.

*Segal, S. P., Hardiman, E. R., & Hodges, J. Q. (2002a). Characteristics of new clients at self-help and community mental health agencies in geographic proximity. *Psychiatric Services, 53*, 1145-52.

Comparative study (survey). Level III-2.

Segal, S. P., Hodges, J. Q., & Hardiman, E. R. (2002b). Factors in decisions to seek help from self-help and co-located community mental health agencies. *American Journal of Orthopsychiatry, 72*, 241-249.

*Segal, S. P., & Silverman, C. (2002c). Determinants of client outcomes in self-help agencies. *Psychiatric Services*, 53, 304-309.

Descriptive study. Level IV.

Shepherd, M. D., Schoenberg, M., Slavich, S., Wituk, S., Warren, M., & Meissen, G. (1999). Continuum of professional involvement in self-help groups. *Journal of Community Psychology*, 27, 39-53.

Silverman, S. H., Blank, M. B., & Taylor, L. C. (1997). On our own: preliminary findings from a consumer-run service model. *Psychiatric Rehabilitation Journal*, 21, 151-159.

*Simpson, E. L., & House, A. O. (2002). Involving users in the delivery and evaluation of mental health services: systematic review. *British Medical Journal*, 325, 1265.

Systematic Review. Primary studies from this review are included in the evidence tables for this critical appraisal. Level I.

Simpson E.L. & House A.O. (2003) User and carer involvement in mental health services: from rhetoric to science. *British Journal of Psychiatry*, 183, 89-91.

Solomon, P., & Draine, J. (1994a). Satisfaction with Mental Health Treatment in a Randomized Trial of Consumer Case Management. *Journal of Nervous and Mental Disease*, 182, 179-184.

Solomon, P., & Draine, J. (1994b). Family Perceptions of Consumers as Case Managers. *Community Mental Health Journal*, 30, 165-176.

*Solomon, P., & Draine, J. (1996a). Service delivery differences between consumer and nonconsumer case managers in mental health. *Research on Social Work Practice*, 6, 193-207³.

Randomised controlled trial. Level I.

Solomon, P., & Draine, J. (1996b). Perspectives concerning consumers as case managers. *Community Mental Health Journal*, 32, 41-46.

Solomon, P., & Draine, J. (2001). The state of knowledge of the effectiveness of consumer provided services. *Psychiatric Rehabilitation Journal*, 25, 20-7.

Stephens, C. L., & Belisle, K. C. (1993). The 'consumer-as-provider' initiative. *Journal of Mental Health Administration*, 20, 178-182.

Stromwall, L. K., & Hurdle, D. (2003). Psychiatric rehabilitation: an empowerment-based approach to mental health services. *Health & Social Work*, 28, 206-213.

Summers, A. (2003). Involving users in the development of mental health services: a study of psychiatrists' views. *Journal of Mental Health*, 12, 161-174.

*Tobin, M., Chen, L., & Leathley, C. (2002). Consumer participation in mental health services: who wants it and why? *Australian Health Review*, 25, 91-100.

Descriptive study. Australasian. Level IV.

*Torrey, W. C., Mead, S., & Ross, G. (1998). Addressing the social needs of mental health consumers when day treatment programs convert to supported employment: can consumer-run services play a role? *Psychiatric Rehabilitation Journal*, 22, 73-5.

³ Solomon and Draine (1995a) and Solomon and Draine (1995b) refer to the same trial reported in Solomon and Draine (1996) at earlier timepoints: only the final article is presented in this report.

Descriptive study (survey). Level IV.

Trainor, J., Shepherd, M., Boydell, K. M., Leff, A., & Crawford, E. (1997). Beyond the service paradigm: the impact and implications of consumer/survivor initiatives. *Psychiatric Rehabilitation Journal*, 21, 132-140.

Vicary, D., & Andrews, H. A. (2001). Model of therapeutic intervention with Indigenous Australians. *Australian & New Zealand Journal of Public Health*, 25, 349-351.

*Wallcraft, J. (2003). Mental health. Pay attention. *Health Service Journal*, 113, 28-9.

Descriptive study. Postal survey of mental health consumer groups. Level IV.

White, J. C. (1989). Consumer participation: a personal journey. *Canada's Mental Health*, 37, 2-4.

Wood, J., & Wilson-Barnett, J. (1999). The influence of user involvement on the learning of mental health nursing students. *Nursing Times Research*, 4.

Yeaton, W. H. (1994). The development and assessment of valid measures of service delivery to enhance inference in outcome-based research: measuring attendance at self-help group meetings. *Journal of Consulting & Clinical Psychology*, 62, 686-94.

Appendix One Service user-run or led mental health services in New Zealand

This list does not purport to be a comprehensive list of services with service users in a governance and/or employment role in New Zealand however it does include those that were easily able to be identified via a phone or website contact as of July, 2004. The index contact person/s change frequently and the details here will be out of date. Some of the services listed are consumer participation services and many operate from within the non-government (NGO) sector. Funding and FTEs vary considerably. A number of services are unfunded or rely solely on voluntary staff.

If you are aware of omissions or updates the Mental Health Commission is interested in obtaining the contact details of any other services or initiatives that meet the definition of service user-run or led service that may be in operation in New Zealand, whether nationally or regionally funded, unfunded/voluntary in nature. Consumer consultancies operating in the business sector are not included on this list.

Centre 401 Trust Kevin Macken PO Box 1183 HAMILTON	The Lighthouse Susie Crooks 25 Clive Square West PO Box 1188 NAPIER	Wellington MH Consumers Union Sarah Porter PO Box 6228 WELLINGTON
Tel: 07 838 0199 psych-survivors@xtra.co.nz	Tel: 06 835 2154 onelight@xtra.co.nz	Tel: 04 801 7769
Psychiatric Consumers Trust Colin Slade 221 Gloucester St 4th Floor, Securities House CHRISTCHURCH	Phobic Trust Marcia Read PO Box 41133 St Lukes AUCKLAND	Oasis network Maria Lynch 14 Laings Rd PO Box 31037 HUTT CITY 04 566 1601
Tel: 03 366 8288 pctrust@xtra.co.nz	Tel: 09 846 9776 clinic@phobic.org.nz	oasisnetwork@xtra.co.nz
Te Tai Poutini Pauline Southorn GREYMOUTH 03 768 5822	Regional Consumer Network Deb Christensen 762 Mt Eden Rd PO Box 10256 Dominion Rd AUCKLAND 09 623 1762	Otago Bipolar Network Don Hillier PO Box 5021 DUNEDIN 03 477 2598
	manager@rcnet.co.nz	otagomd@es.co.nz
Pathways to Wellbeing Teresa Keedwell PO Box 5010 PALMERSTON NORTH 06 350 8038	Te Whare Atawhai Esther Oliver 186 Chapel St MASTERTON 06 370 8993 dropin@ihug.co.nz	Kapiti Choices Nelson Cressy 19B Milne Drive PO Box 597 PARAPARAUMU 04 905 2110 kapitichoice@paradise.net.nz
GROW NZ Inc Ruth Williams PO Box 41051 St Lukes AUCKLAND 09 846 6869	Te Roopu Pookai Taaniwhaniwha Karen Walker 213 Bedford St PO Box 50577 PORIRUA 0 237 9608	Central Potential John Tovey PO Box 9762 Marion Square WELLINGTON
enquiries@grow.org.nz	john.tovey@taaniwhaniwha.org.nz	04 382 9600 027 279 3666 john.tovey@taaniwhaniwha.org.nz

Te Ata
Glyn Allan
14 Hickory Ave
HENDERSON
09 837 0671

te-ata@xtra.co.nz

Clubhouse
Chris Adamson
PO Box 78110
Grey Lynn
AUCKLAND
09 376 4267

clubhouse@xtra.co.nz

Psychiatric Survivors
Julian McClusky-Dixon
Apt 1, 4 Warnock St
Grey Lynn
AUCKLAND
09 376 7164
021 260 7407

CAN Trust
Jill Doms
c/- Compass Community
Village
17th Ave
TAURANGA
07 578 6934

bopconsumergroup@xtra.co.nz

Eastern BoP Consumer Advisory
Group
Lila Baker
7 Arawa Rd
WHAKATANE
07 308 0972

basliila@xtra.co.nz

Turning Point
Arlene Foster
PO box 9217
Greerton
TAURANGA
07 578 6934

turningpoint@xtra.co.nz

Serious Fun 'n' Mind
Cate Light
c/- 6c Good Rd
TAURANGA

07 574 1404

seriousfunmind@xtra.co.nz

Nga Morehu Whai Ora
Lena Simeon-Miles
42 Water St
PO Box 67
WHANGAREI

09 438 2421

Toi Ora
Charlton James

09 360 4171

Te Kupenga
Charmaine Turei
93 Derby St
GISBORNE

06 868 4045
027 283 1981

Stepping Out Hauraki
Marie Reilly
100 Sealey St
THAMES

07 868 5595

stepout@paradise.net.nz

Step Ahead
Linda Simson
167 Stanmore Rd
PO Box 32025
CHRISTCHURCH

03 389 4001

info@stepahead.org.nz

Southern Consumer
Network
Elizabeth Biddington
4th Floor, Securities House
221 Gloucester St
CHRISTCHURCH

03 366 8288

ebiddington@actrix.co.nz

The White House
349 Trafalgar Square
NELSON

[mailto:twh@actrix.co.nzmailto:tw
h@paradise.net.nztwh@paradise.
net.nz](mailto:mailto:twh@actrix.co.nzmailto:tw
h@paradise.net.nztwh@paradise.
net.nz)

Graham Kirkham
PO Box 105
Eltham
Taranaki

06 764 5258

grahamandjanine@xtra.co.nz

BALANCE, New Zealand
Bipolar and Depression
Network
Carolyn Doughty
PO Box 13266
CHRISTCHURCH

03 366 3631

bipolar@balance.org.nz

Wanganui Bipolar Network
Frank Bristol
PO Box 7210, Mid Avenue
WANGANUI

06 343 8779

frank@balance.org.nz

Wellington Bipolar Support Group
PO Box 27545,
Marion Square,
WELLINGTON

04 494 0424

wellington@balance.org.nz

Bipolar Support Canterbury
Lynere Wilson
PO Box 25 068,
221 Gloucester Street
CHRISTCHURCH

Ph: 03 366 815
bipolarsupport@xtra.co.nz

Depression Support Network
P O Box 13 167
221 Gloucester Street
CHRISTCHURCH

Ph: 03 366 8083
depression.net@xtra.co.nz

Hawkes Bay Bipolar Group
210 Nelson Street
HASTINGS

027 427 5177 or
027 292 5642

emgardiner@xtra.co.nz

Depressive Disorders
Support Group
Phillipa Crocker
PO Box 1183
HAMILTON

Ph: 07 838 0199
ddsg-wko@ihug.co.nz

Promoting Mental Wellness
David Baker
PO Box 7208
Hamilton East.

Ph: 07 8564265
pmwellness@ihug.co.nz

ThroughBlue
Womens Depression Support
Group
Katie Chalmers
Wellington

throughblue@hotmail.com

Appendix Two Search Strategies

Medline

- 1 ((consumer\$ or peer\$ or survivor\$) adj (run or managed or led or driven or initiated)).mp. (301)
- 2 patient managed.mp. (405)
- 3 psychiatric survivor.mp. (2)
- 4 service user.mp. (76)
- 5 patient led.mp. (193)
- 6 self help.mp. (2327)
- 7 *Self-Help Groups/ (2795)
- 8 *community networks/ or *social support/ (8198)
- 9 exp *Consumer Participation/ (9199)
- 10 or/1-9 (22289)
- 11 exp *Mental Health Services/ (26680)
- 12 *Mental Disorders/ (51836)
- 13 *community mental health centers/ or *community mental health services/ (9582)
- 14 or/11-13 (74922)
- 15 10 and 14 (1263)
- 16 limit 15 to (english language and yr=1980-2004) (1061)
- 17 exp Substance-Related Disorders/ (136373)
- 18 16 not 17 (980)
- 19 letter.pt. (514161)
- 20 Case Report/ (1103824)
- 21 18 not (19 or 20) (919)
- 22 from 21 keep [SELECTED REFERENCES] (40)

PsychInfo

- 1 ((consumer\$ or peer\$ or survivor) adj (run or managed or led or driven or initiated)).mp. (272)
- 2 patient managed.mp. (15)
- 3 psychiatric survivor.mp. (7)
- 4 service user\$.mp. (449)
- 5 patient led.mp. (23)
- 6 self help.mp. (4138)
- 7 *social support networks/ (10971)
- 8 exp *self help techniques/ (3341)
- 9 *social networks/ (1002)
- 10 or/1-9 (18358)
- 11 mental health services/ (10294)
- 12 mental disorders/ (25742)
- 13 exp Mental Health Programs/ (5442)
- 14 community mental health services/ (4245)
- 15 or/11-14 (42116)
- 16 10 and 15 (1085)
- 17 limit 16 to (english language and yr=1980-2004) (1016)
- 18 exp drug abuse/ (42279)
- 19 17 not 18 (941)
- 29 from 19 [SELECTED REFERENCES] (56)

Embase

- 1 ((consumer\$ or peer\$ or survivor\$) adj (run or managed or led or driven or initiated)).mp. (196)
- 2 patient managed.mp. (324)
- 3 psychiatric survivor.mp. (3)
- 4 service user.mp. (66)
- 5 patient led.mp. (133)
- 6 self help.mp. (2646)
- 7 *Self-Help Groups/ (618)
- 8 *community networks/ or *social support/ (3620)
- 9 exp *Consumer Participation/ (529)
- 10 or/1-9 (7416)
- 11 exp *Mental Health Services/ (2919)
- 12 *Mental Disorders/ (16066)
- 13 *community mental health centers/ or *community mental health services/ (3020)
- 14 or/11-13 (18776)
- 15 10 and 14 (409)
- 16 limit 15 to (english language and yr=1980-2004) (380)
- 17 exp Substance-Related Disorders/ (45560)
- 18 16 not 17 (362)
- 19 letter.pt. (263398)
- 20 Case Report/ (563339)
- 21 18 not (19 or 20) (343)
- 22 from 21 keep [SELECTED REFERENCES] (24)

Cinahl

- 1 ((consumer\$ or peer\$ or survivor\$) adj (run or managed or led or driven or initiated)).mp. (156)
- 2 patient managed.mp. (31)
- 3 psychiatric survivor.mp. (1)
- 4 service user.mp. (79)
- 5 patient led.mp. (12)
- 6 self help.mp. (798)
- 7 *Self-Help Groups/ (1620)
- 8 *community networks/ or *social support/ (4243)
- 9 exp *Consumer Participation/ (1349)
- 10 or/1-9 (7735)
- 11 exp *Mental Health Services/ (6710)
- 12 *Mental Disorders/ (3628)
- 13 *community mental health centers/ or *community mental health services/ (1642)
- 14 or/11-13 (9804)
- 15 10 and 14 (373)
- 16 limit 15 to (english language and yr=1980-2004) (366)
- 17 exp Substance Abuse/ (7175)
- 18 16 not 17 (361)
- 19 letter.pt. (18867)
- 20 Case Studies/ (2914)
- 21 18 not (19 or 20) (355)
- 22 from 21 keep [SELECTED REFERENCES] (46)

Keyword search for peer

- 1 ((consumer\$ or peer\$ or survivor\$) adj (run or managed or led or driven or initiated)).mp. (295)
- 2 patient managed.mp. (19)
- 3 psychiatric survivor.mp. (7)
- 4 service user\$.mp. (502)
- 5 self help.mp. (4511)
- 6 *social support networks/ (11475)
- 7 exp *self help techniques/ (3488)
- 8 *social networks/ (1051)
- 9 patient led.mp. (36)
- 10 or/1-9 (19456)
- 11 mental health services/ (11069)
- 12 mental disorders/ (31478)
- 13 exp mental health programs/ (6033)
- 14 community mental health services/ (4486)
- 15 or/11-14 (49173)
- 16 10 and 15 (1167)
- 17 16 (1167)
- 18 limit 17 to (english language and yr=1980-2004) (1094)
- 19 exp drug abuse/ (47219)
- 20 18 not 19 (1015)
- 21 peer counseling/ or peer tutoring/ or peers/ (3461)
- 22 peer\$.ti. (7569)
- 23 15 and (21 or 22) (132)
- 24 23 not 20 (112)
- 25 24 (112)
- 26 limit 25 to (english language and yr=1980-2004) (82)
- 27 from 26 keep 5,8,10-11,14,16-17,25-26,36,50,52,54,57,60-61 (16)

Databases searched (using the search strategies outlined)

Bibliographic databases

Medline, PsychInfo, Embase, Current Contents, Cinahl, Web of Science and Index New Zealand.

Other sources of information

In the preliminary search undertaken for this review, additional sources searched included major online library catalogues, website sources such as evidence-based and guidelines sites, government health websites, related health professional association websites, and major websites.

Review databases

Cochrane Database of Systematic Reviews and DARE Database of Abstracts of Reviews of Effectiveness .

Library catalogues

New Zealand bibliographic database Te Puna, LocatorPlus (National Library of Medicine), CoPAC (Combined University Catalogues UK) and WHOLIS.

Government websites

New Zealand

Te Puna web directory, Mental Health Foundation and Ministry of Health.

Great Britain

Department of Health and Mental Health Foundation

Australia

Australian Department of Health and Ageing

United States

Center for Disease Control CDC

Canada

Health Canada

Associations and organisations

National Resource Centre for Consumer Participation in Health

<http://www.participateinhealth.org.au>

London Mental Health Research & Development: Virtual Institute [LoMHR&D]

<http://www.virtualinstitute.co.uk/>

National Mental Health Consumers' Self-Help Clearinghouse

<http://www.mhselfhelp.org/>

Consumer Operated Services Program

<http://www.cstprogram.org/cosp/>

Other Websites

<http://www.mhamerica.org/research>

Search engines and directories

Google

SearchNZ

Organised Networked Medical Information (OMNI)