NSW

Working on strengths …the evidence so far

models of assistance by mental health community organisations and evidence of their effectiveness

PRE-RELEASE DRAFT FOR EXPERT PEER REVIEW, 2007
UPDATE AND SECTOR NOMINATION OF FURTHER STUDIES

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representing Non Government Organisations (NGOs) working for community mental health

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Working on Strengths is based upon an MHCC Evidence Audit [1] of the international literature of evaluated psychosocial rehabilitation, resilience and recovery programs.

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Acknowledgment

New Zealand's *New Directions* report [2] prepared to inform the New Zealand government's 'Blueprint' for mental health reform also reviewed non-government mental health service models in light of international program evaluations to 1996. *Working on Strengths* made reference to New Directions in articulating some programs in common between New Zealand and New South Wales. *Working on Strengths* re-examined the primary studies in New Directions and systematically reviewed the last decade of research findings to April 2006. A preliminary update of the review was of literature to January 2007.

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2007 Update

Review comments for the 2007 update may be sent to MHCC attention Jonine Penrose-Wall or may be emailed to jonine@iimetro.com.au or Mob 0409 741414

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Foreword

In a recent journal of psychiatry, Julian Leff [3] suggests that the complexity and invisibility of modern mental health care can be confused to mean that the move to community has failed. He explains: a good mental health service in the community is virtually invisible. Residences are indistinguishable from those of their neighbours, staff work in converted houses, and the 'dramatic architectural presence of the asylums has been replaced by an apparent absence'.[3] In New South Wales, decades before the hospitals downsized, communities were organising themselves to help those with mental health needs.

Working on Strengths makes visible the successful network and services of voluntary non-profit community **mental health** organisations (or non-government organisations) in New South Wales. They quietly perform the every day tasks of supporting and rehabilitating people with or having had mental illness to move from strength to strength in their lives. Through NGO programs of assistance people in recovery achieve outcomes that may be unlikely without these psychosocial programs: they get back to work or to running households and they learn how to prevent a relapse that would otherwise lead to the use of hospitals, emergency departments and GPs. NGOs also develop new programs, including those that can be run by consumers, lay people and volunteers.

Working on Strengths introduces the broad program logic of these interventions and presents the limited research evidence for these programs that is so far available. It aims to inform individuals and organisations in the field and those wanting to work in partnership with NGO programs.

Leone Crayden
Chair
Mental Health Coordinating Council of New South Wales Inc
April 2006

Care in the community has not failed as sometimes alleged…

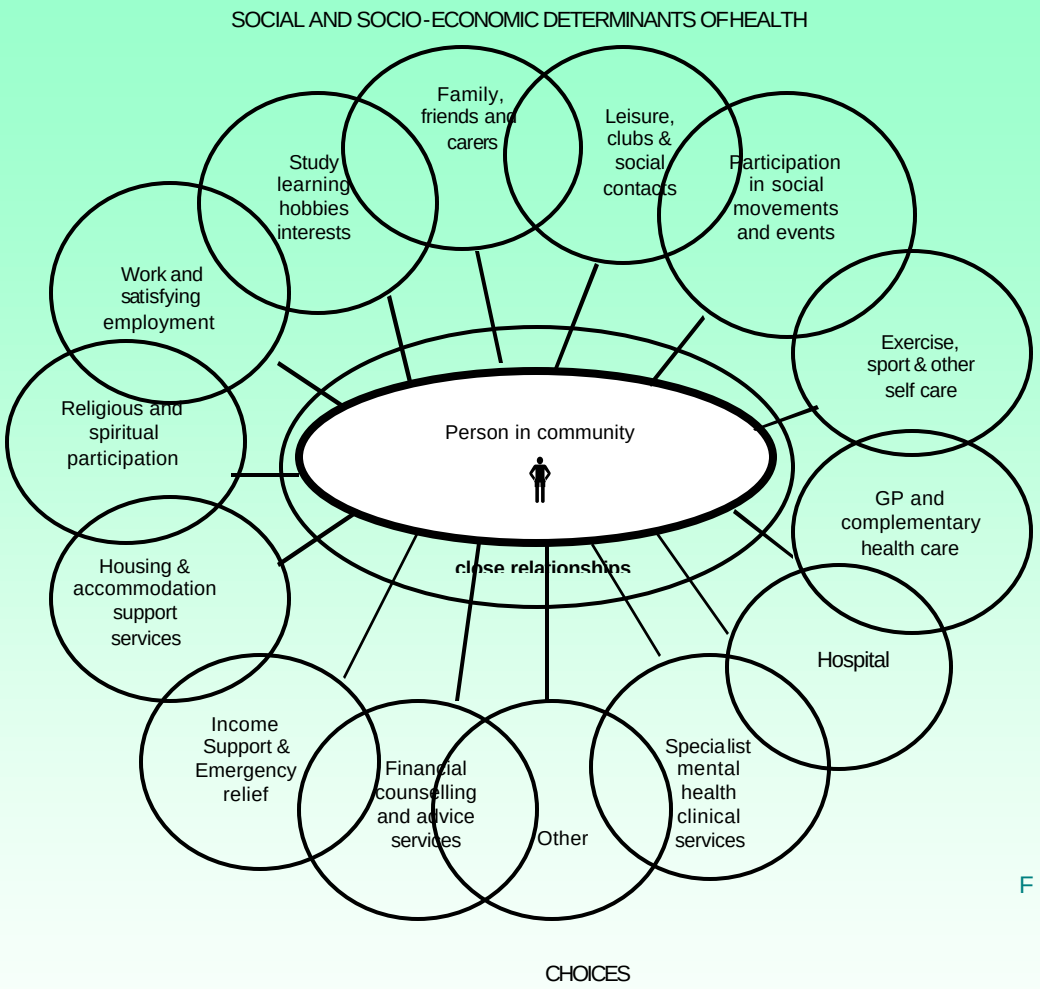


Figure 1: 'Inclusive community'

Non-government mental health organisations ('community organisations') assist all persons to fully participate in community life…

Introduction

The first community organisation for mental health in New South Wales was the After Care Association. It was established in 1907 to provide shelter and support to people leaving psychiatric hospitals.

We *are* the community…
caring since 1907

Today, non-profit, voluntary-managed community organisations, or non-government organisations (NGOs), both prevent and respond to mental health problems. Their resilience, recovery and rehabilitation programs tap strengths in people to resume their lives after experiencing crisis, trauma, disasters and disabling forms of mental illness. For those with more prolonged difficulty or disability arising from mental illness, community organisations help the person re-establish routines, find and maintain supports and make choices to find meaningful future roles. Most of this is done within the fabric of community where people live out their lives rather than in hospitals or health centres. NGOs also help people to access a range of treatment services (as shown in Figure 1) and advocate for the quality and supply of a range of mental health services.

Working on Strengths can be used by:

- individuals in recovery who want to know more about NGO programs
- psychiatrists and clinicians so they may refer people to community rehabilitation and support
- policy makers and funders
- citizens and corporations wanting to volunteer time or make donations to mental health NGOs.

Working on Strengths reports the models of assistance used by NGOs and the public health rationale for these approaches. It reports the research evidence for their effectiveness and cost effectiveness. It also reports **research gaps** and where we only know of the popularity of programs rather than their effectiveness.

What mental health NGOs do …

Community organisations intervene upon wider sets of life problems, risk conditions, problematic community attitudes and psychosocial needs than do public mental health services. The latter witness these wider problems and may expertly understand them. But scarce government health services may be narrowed to symptom relief, time-limited case management and referring on, rather than undertaking the longer-term work of assisting sometimes broken lives to get fully on the mend.

'Psychosocial rehabilitation' is a set of processes, which aim to decrease disability and handicap. Its procedures should be oriented to the activation of human and material resources available.[4] While the 'clinical' versus 'psychosocial rehabilitation and disability support' distinction between government and NGO mental health services is not always absolute, community organisations nonetheless provide complex care and sometimes continuous health care over long periods of a person's recovery. For example, they …

- provide outreach and support to prevent the worsening on mental health problems;
- meet material and welfare needs and often provide or broker housing arrangements;
- provide emotional support to prevent isolation and marginalisation;
- encourage people to stay in treatment and provide information about treatment;
- help people to re-establish their lives after psychiatric hospitalisation;
- link people to jobs and maximise labour market participation;
- help prevent suicide by detecting those at risk and helping those bereaved;
- provide facilities to consumers to run their own programs;
- provide professional therapeutic counselling and other models, like peer-counselling;
- publish information on illness self-management and run tailored rehabilitation programs;
- offer a sense of community while linking people with opportunities in wider society;
- fund raise to enable other citizens to help promote and protect mental health; and
- prevent negative outcomes such as suicide, harmful drug misuse or imprisonment.

Service type of NSW NGOs in mental health (Bateman & Johnston, 2000)	% (number)
Consumer support groups (illness related)	43 (160)
Community consultative committees	10 (36)
Carer support groups	10 (39)
Supported residential services	9 (33)
Advocacy, education and information services	7 (26)
Open employment services	5 (19)
Telephone support services	5 (18)
Drop in centres and Clubhouses	4 (13)
Supported Employment Services	2 (9)
Consumer networks	2 (9)
Respite services	2 (6)
Outreach services	1 (4)
Total (services not NGOs)	100 (372)

Outcomes

Figure 2 simplifies the awkward distinction for an individual, between the foci of mental health programs provided by non-profit community organisations and those provided by public mental health services in NSW.

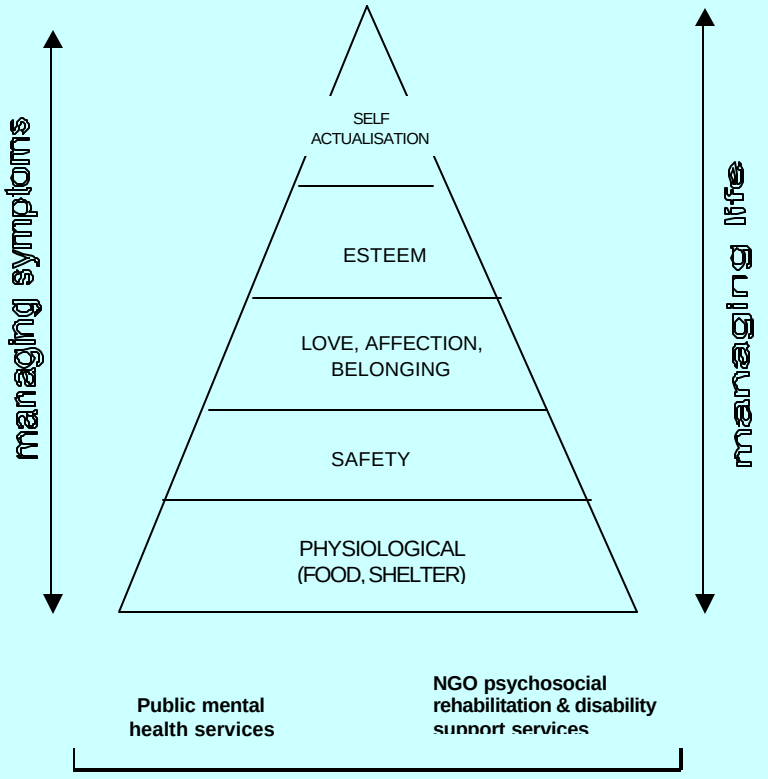
Outcomes for 'clinical' public mental health services typically focus on symptom control and managing disease severity. Mental health clinicians also provide assertive case management in the community where their role has much in common with the case management and or 'outreach support' performed by NGOs. Clinicians also monitor the effectiveness and acceptability of medications to consumers. Both NGOs and clinicians help carers.

It is the pressure of demand that sometimes limits public clinical services to a focus on symptoms. Community organisations on the other hand, help people to manage their lives (regardless of symptoms) — where to live, personal care, responsibilities for others, getting back to work and managing relationships. Generally speaking, NGOs tend to focus upon strengths, not deficits.

The persons served may also differ: in community organisations consumers are often well enough to take charge of their own recovery, but they may need practical life assistance and support. This 'support' includes structured psychosocial rehabilitation. If these life conditions are stable, fewer symptoms are usually experienced. If symptoms are not under control, they impact on at least some aspects of life, causing set-backs. Such set backs are then the focus of the consumer learning to tap their strengths to manage the illnesses in the context of life challenges.

Importantly, symptom control on its own does not mean that all aspects of life click into place. Reclaiming independence and recovery can require tailored rehabilitation and individualised **psychosocial disability support *with* (not instead of) evidence-based psychiatric and psychological treatments.**

Figure 2: Adapted model of Maslow's 'hierarchy of human need' showing the roles of both public ('clinical') and NGO (psychosocial) programs



COMMON GOAL: maximize synergies between evidence-based clinical and evidence-based psychosocial rehabilitation programs [5]

Effective contemporary evidence-based programs for people in recovery from mental disorders try to achieve a synergy between treatment programs and psychosocial rehabilitation programs with cooperation, effective communication and operational links between service systems and service providers. [5 - 9]

Method

We systematically appraised English language evaluative research to April 2006 to summarise evidence on the likely effectiveness of NGO mental health programs ('evidence audit'[1]). Few such evaluations exist in Australia, so an attempt was made to find effective programs **or the ingredients of effective programs** elsewhere that have been evaluated, since these provide the kernel of the evidence-base for similar programs used by NGOs in NSW. We had previously mapped models of assistance (what NGOs actually do) from repeated surveys of the then 144 organisational members of the Mental Health Coordinating Council of NSW Inc (MHCC)[9,10]. The focus of our search was principally **adults in recovery from schizophrenia** and we took into account comorbid substance misuse and addiction. We included a wider search for self-help groups (mood, eating and anxiety disorders). The method included:

- systematic literature reviews published in peer reviewed journals;
- government-commissioned systematic literature reviews;
- English language current clinical practice guidelines (Australia and New Zealand);
- published and unpublished NGO program evaluations;
- primary studies of program evaluations published in peer-reviewed journals;
- Cochrane Database of RCTs and Cochrane Library of Systematic Reviews;
- PhD theses on NGO Websites and in the Australian Digital Theses Database; and
- International research registers and international NGO websites.

Levels and quality of evidence

We apply NHMRC's 'levels of evidence' (Appendix 1) in bold text.[11] While few NGO programs in Australia have been evaluated using randomised controlled trials (RCTs) programs overseas sometimes have been. Those evaluations

from good will
to good services:

voluntary, community-managed services must be evaluated to put good will to good effect.

provide an **estimate of potential effectiveness** but should not be taken to mean that evaluations are not needed locally. Local programs need evaluating to see if they have fidelity to the original programs, or where modified, that the local program is appropriate, effective and cost effective. The higher the level of evidence rating ('I' is highest), the more appropriate it is for the program to be disseminated or replicated.

'Effectiveness'

A program is 'effective' if it does more good than harm under real world conditions.[12] It must also meet criteria in trials for 'efficacy' which means the extent to which a program does more good than harm under optimal conditions. Programs must do well on the majority of reported outcomes with at least one outcome showing statistically significant positive effects and there must be no negative effects on any important outcomes.[12]

Programs must be low cost since NGOs must raise funds to seed and sustain their programs and they offer most programs at no cost or low cost to users. It is important to know for whom programs are effective, at what level of exposure and for how long the effective program has effect for the individual or group of participants.

'Good practice' models in the absence of evidence can be deemed so through opinion alone. Such programs are highly acceptable to consumers and their popularity evokes confidence that they do no harm. But we often don't know if they in fact do good, or exactly what good they do. We know little about the intensities at which psychosocial programs are needed for different groups.[13][14]

It is thus preferable that programs be evaluated, going from (a) innovative idea (below) to an initial descriptive evaluation, then to be subjected to the scrutiny of controlled trials. It is not until success is demonstrated through repeated highest quality evaluations feasible (to see if other workforces, sometimes lay persons, can achieve the same result) that they are deemed 'effective'. More likely,

programs can be demonstrated to be ‘promising’ since evaluation is expensive and it is difficult to achieve results that prove effectiveness. Few NSW NGO programs have been so evaluated [1]whereas the ideal would be an evidence base for NGO programs at levels (d) and (e) below.

Here we use the terms, ‘effective’ and ‘promising’ in this context, strictly linked with NHMRC ‘level of evidence’ ratings which health consumers are familiar with (these refer to the study designs necessary to answer research questions about effectiveness). We conclude that the consumer confidence enjoyed by many NGOs must now lead to quality initiatives informed by a higher quality of evidence derived where feasible from local program evaluation.

Mental health NGOs in NSW are ‘hands-on’. They do not have research, evaluation and development (RED) infrastructure. They are funded to deliver programs rather than strategically evaluate their work, but all industries require industry-based RED.

A flourishing community organisation sector must ensure industry-based RED to progress the use of and test evidence-based programs through which to progress service delivery, design and innovation.

Program evaluation status

a) Innovation — emerging program model, not yet described in peer reviewed published literature, and not yet evaluated

↓

b) Model has been described, even replicated, but effectiveness is unknown

↓

c i) Evaluated overseas as effective for defined population when delivered by clinicians
c ii) Evaluated in Australia as effective for defined population when delivered by clinicians

↓

d i) Evaluated effective for defined population when delivered by NGO overseas
d ii) Evaluated effective for defined population when delivered by NGO in Australia

↓

e) Model is refined and evaluated as effective and cost effective for dissemination in NSW by NGOs

NGOs quickly identify community need and can innovate new ways of responding…

NGOs now need real world local evaluations to shape innovation to help more people more quickly and meet more complex needs

models of assistance

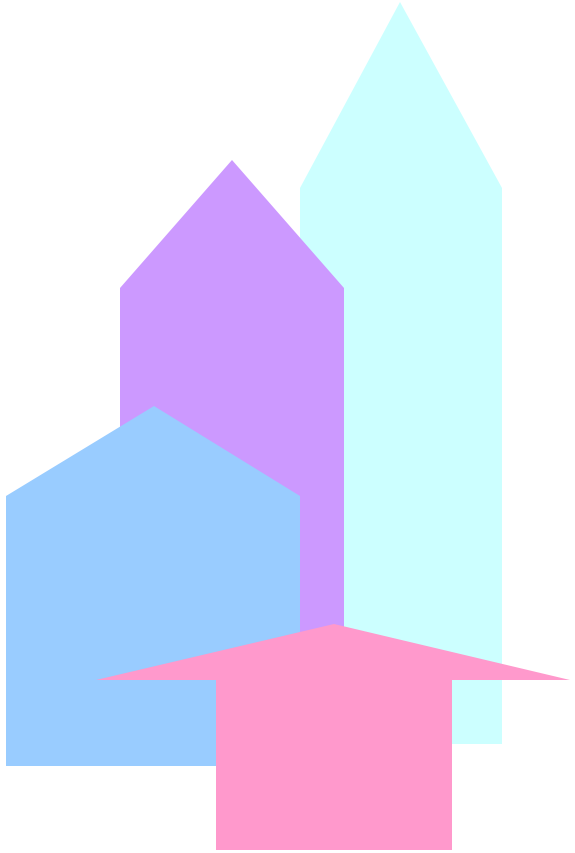
and

evidence of effectiveness

In 2006, 144 NGOs provided 372 programs of assistance (funded and self-funded) for mental health needs in NSW[9]

By 2007, 154 NGOs were members of the Mental Health Coordinating Council Inc.

Accommodation support & outreach



TARGET POPULATION

- people in recovery from psychotic disorders, other disabling and co-morbid mental disorders;
- who need support to manage their illness and live independently (some may have just left hospital);
- and may be unable to work or will gradually return to work and need affordable housing; or
- people who are homeless or are at risk of homelessness and have mental illness.

NSW Health's policy framework for supported accommodation [7] reports six groups of people with decreasing illness severity who have different needs for staff-supported accommodation. Persons in an acute or post-acute phase of illness may need hospitalisation or 24-hour staffed residential rehabilitation while individuals in recovery require NGO-provided / managed accommodation, with daily or weekly support or support as-required. NGOs also see people when acutely ill and provide safe accommodation in ways that avoids them having to go to hospital. Although NGOs can provide private hospital care, NGOs usually provide community supported accommodation in four of the NSW Health identified categories. The NGO as landlord is now discouraged in this policy.

RATIONALE

Supported accommodation makes living in the community possible including for persons with continuing symptoms or with disabilities in managing on their own. Housing is also a prerequisite for relapse prevention [6 24] and for most other social integration, quality of life, protection from poverty and other outcomes. Housing facilitates 'a place' from where people can get on with their lives — it provides stability during illness recovery. 'Support' may be material or emotional and reduces some life stressors while optimising independence and self-responsibility.

Supported accommodation is conceptualised as part of the pathway *from*

hospital or more formal types of care rather than a pathway *into* care. However, living with mental illness with NGO support does not always replace the need for clinician-delivered help. Usually, public mental health teams provide 'clinical' services while NGO programs deliberately provide more normalised environments for recovery called (broadly), a 'psychosocial rehabilitation' approach.[2 4 5 13 -15] NGO programs generally encourage people to continue their treatment in environments that provide hope and information reporting the choices of treatments and that treatments generally work for most people.

But unlike hospital or mental health team rehabilitation, NGOs don't simulate 'living in the community', NGOs ARE the community, managed and made up by community members. They use the whole community (theoretically) to help people find what they need to recover. NGO programs are done with rather than instead of clinical services, the latter being a vital resource.

Having said that clinical mental health team care may continue, complete reliance upon them alone is diminished through NGO-provided supported accommodation. NGOs help the person in recovery to rebuild other supports and therapeutic experiences in their lives from elsewhere. NGO services offer an alternative 'less restricted environment' than hospital or day hospital. NGO programs may be short term, medium term, long term or with no time limit.

Complete reliance on family is also diminished. But NGOs also provide information, care and support to partners and family members.

BACKGROUND

NGOs have a Century of experience providing supported accommodation in NSW. Today, example NGOs providing accommodation include the Richmond Fellowship (a founding organisation of the therapeutic community movement in Australia); the Aftercare Association; B Miles Womens Housing; Mental Health Accommodation and Rehabilitation Services (MHARS) and NewHorizons.

The early Therapeutic Community (TC) approach (1950s-1980s) requires

'Place' enables local relationships, employment and civic engagement.

discussion. It was found beneficial for those with and without mental disorders. But it was not cost effective for widespread adoption. Social psychiatrists and social scientists collaborated in the science of the movement and showed early that lay people and disciplines other than medicine had a role in providing effective rehabilitation environments as alternatives to hospital (see Nick Manning texts). The TC movement gave way to more affordable models. TC elements remain in some NGO programs. It continues to be used experimentally as an 'ideal' (not real world) program type to see if some complex mental illnesses are treatable through social approaches. TC was recently shown to reduce more drug use and psychopathology for homeless people with mental illness than just community residences. [16]

MODELS

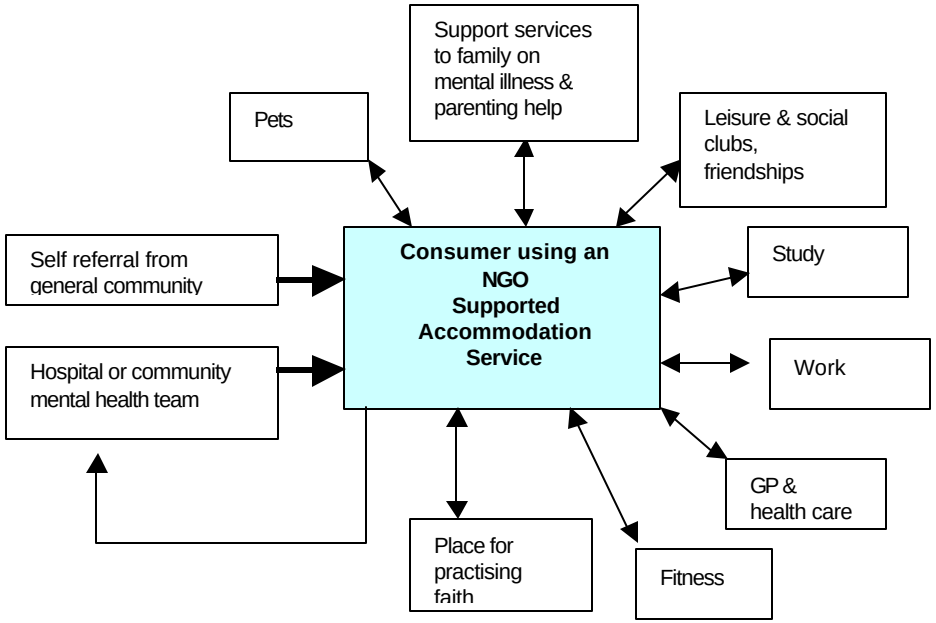
- Supported accommodation (residential services or support to individual tenants)
- Respite care (short-term support to those with family support)
- Outreach
- Partnership models with Area Mental Health Services (eg HASI)

NGOs provide accommodation either on a rental basis where the NGO owns the housing stock, or the NGO acts as landlord for State Housing-owned housing stock. Few, if any, NGOs provide housing without practical or emotional support. Womens accommodation programs often assist or accommodate children and assist women with mental illness with parenting. They may also address sexual assault and recovery, or support women in leaving violent relationships.

'Supported accommodation' is the term used in the evaluation literature. Literature evaluating models of 'case management' forms part of the evidence base for accommodation models.

Case management is not a therapy. It is more a way of organising a service's workload. Models of accommodation vary depending on where staff members are located (on site, in a nearby office, or at a centre with an outreach role) and the intensity and duration of case management provided. [27] Within ' outreach' (or

within 'case management') there may be numerous additional aspects of therapeutic contact. Evaluations usually focus on reducing rehospitalisation in order to establish community care as equally effective, or more effective, but more cost effective and acceptable than hospital care. Mueser and colleagues (1998) outline the key models of 'case management'[17] and most of these reflect NSW NGO approaches directly, or have similar elements to NGO programs.



Negative outcomes avoided:

- Homelessness
- Symptoms worsening
- Illness recurrence
- Return to hospital
- Justice system involvement
- Isolation
- Suicidality
- Rejection by community
- Poor physical health

Figure 3: Summary logic of an NGO supported accommodation program using a brokerage model of case management which mobilises resources in the environment

The **brokerage or extended brokerage** model is common in NGOs (Figure 3) and at minimum involves linkage and referral to a range of supports in the environment [2 17]. In this model, NGOs do not provide clinical care but link consumers to clinicians. The model assumes the availability of the latter and is for consumers who are less likely to need repeat rehospitalisation. NGOs provide where possible, single-occupant dwellings with outreach support in ways which overcome loneliness and isolation and maximise contact with others. It allocates a 'key worker' for assessment, problem solving, linking with resources and meeting needs as they arise.

In the **strengths model** one can recognise traditional social work and some NGO strengths-based traditions. It is relational rather than structural [2] and aims to facilitate success in the environment using the person's 1) strengths 2) the resourcefulness of community 3) consumer self determination 4) relationship skills 5) intensive outreach to foster relationships with community and 6) an expectation of positive recovery. It aims to decrease NGO involvement over time. [17 18]

A **rehabilitation model** of case management is also used by some NGOs where the consumer selects his or her goals and uses skills to maintain adaptations in the environment (Figure 4). [17]

In the literature these models are called, 'intensive' (and / or 'assertive') case management generally found appropriate for people with severe to moderate disability where provided by NGOs. [2 17-22] Strengths case management is more often used for more independent consumers. [18]

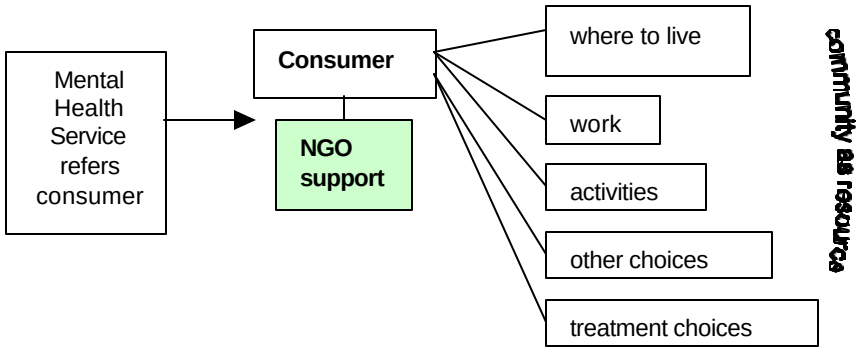


Figure 4: NGO supported accommodation using rehabilitation model of case management: consumer develops skills based on choices/goals

Some users of NGO-accommodation may also have NSW Health case manager visits. The latter team-based '**clinical case management' also uses intensive assertive** community treatment models but with teams of clinicians and evaluated in Australia with confidence for preventing relapse and improving health outcomes. [22] Intensity of assistance differs around what the consumer already has access to from the NGO, and illness severity. Generally, clinician visits aim to engage the person in treatment longer where they have more severe disability, unstable illness characteristics and/or ongoing risk for relapse.

Assertive community treatment (ACT) may also be used for consumers still in an acute phase of illness, but staffing these programs without trained clinicians is advised against [6, 22] for this group since it may compromise community tenancy. Assertive models of case management with added psychosocial programs have been effective to re-engage disaffected homeless people with mental illness, a group often assisted by some NGOs. [23]

Negative outcomes avoided:

- Homelessness
- Illness recurrence
- Return to hospital
- Justice system involvement
- Isolation
- Suicidality
- Rejection by community
- Poor physical health
- Pow erlessness and dependence

All models have been evaluated to achieve engagement with staff. They have moderate impacts for improving some symptoms, use of medication [20] quality of life and relapse prevention, but they do not necessarily always improve mental state **(I).** [26, 27] In one study, the strengths model, used by a multidisciplinary team, when compared with assertive community treatment for those with severe psychiatric disability, was superior and reduced symptoms by half **(III-2).** [25] There is debate as to the impact of case management on negative outcomes such as imprisonment or vocational outcomes **(I).** [22, 26, 27] Case management / care coordination can be over relied upon as if it is itself a therapy, whereas the intent is to build specific helpful interventions into broad case management frameworks.

International research **(III-3 to II)** shows that **consumers** can be effective when employed in case management teams or as sole case managers for less disabled clients, but more research is needed to know how best to apply consumer skills in these roles. [28, 29]

Finally, **partnership models of supported accommodation** involve more than scheduled case management visits of the sort under assertive case management. They are justified because routinely collected service data suggest that clinician visits decline where consumers live in NGO supported accommodation at times when clinicians experience pressured case loads [9, 30, 31].

Partnerships [8] aim to increase **reliable access** to community accommodation because more intensive support is certain and sustained. Intake policies are more inclusive of consumers who might be disadvantaged in accessing a community placement. Partners organisations agree on a structured arrangement in planned share care with cooperation at a system and operational level around structured protocols or care pathways. They may also share outcome evaluation responsibilities, information systems or other infrastructure.

The NSW Government's Housing and Accommodation Support Initiative (HASI)

is an example and involves NGOs, NSW Health Area Mental Health Services and NSW Department of Housing working together to ensure successful community tenancy. The third evaluation report was released in January 2007. Earlier results showed that more intensive and integrated care achieves better outcomes and up to 74% reduced hospitalisation, 93% consumer satisfaction with housing, 90% fall in hospitalisation, 85% maintaining tenancy and over half the consumers learning relevant social and independence skills.[33] The later evaluation showed that the joint approach increases a participant's participation in the community, strengthens social networks. A 20% increase in living skills was shown among other positive outcomes.

PREFERRED PRACTICE MODELS

There are 33 NGO supported accommodation programs (9% of NGO mental health programs) with NGO-provided or managed housing, 4 NGO outreach and 6 NGO respite programs in NSW for people with or having had mental illness. The preferred model depends ultimately on consumer choice and on the consumer group being served[22, 6] with less intensive models being able to be performed by non-clinicians [22] who are most often employed in NGOs. Preferences include:

- sole-occupant or own accommodation (supported individual tenancies) **(V)**;
- with mobile clinical **and/or** non-clinical (NGO psychosocial) support **(I, II)**;
- with **guaranteed** clinical **and synthesised with** non-clinical (NGO psychosocial) support for high support consumers **(II, III-2)**;
- where linkages to community life are active to mobilise resources in the environment **(I)**;
- where frequency and quality of key worker contact emphasises strengths, choice and optimism **(I)**; and
- where peer-to-peer support is possible, and where consumer participation is valued **(V, II)**.

EVALUATIONS OF NGO PROGRAMS

In the international research a Cochrane review concluded that housing schemes with on site staff may provide both a 'safe haven' and dependency. Risks and benefits require more investigation since dependency may be an

avoidable adverse outcome. [27] This is relevant to NGOs who aim to provide 'community' within community or a continued sense of community rather than necessarily being a pathway out of formal care and away from service contact entirely. It is often the consumer's choice when to leave the program.

Recent NSW Health-commissioned HASI program evaluations [32] and other published commissioned needs assessment of NSW NGO accommodation programs [33] provide evidence of promising models. These involve NGOs providing supported accommodation to people with long histories of hospitalisation, including when provided in a service partnership context.

Overall, the most evaluated models are (non-NGO) clinical assertive community treatment from clinician-staffed housing schemes, which aim to replace hospital care.

Apart from approximately 24 texts (including NSW experience) that exist on the conceptual basis of psychosocial and milieu care from the older therapeutic community era, NGOs are under-represented in the evaluation literature.

More evaluation of their contribution is needed especially given that consumers have high reliance on their programs.

Employment & supported employment

TARGET POPULATION

- people in recovery from psychotic disorders, other disabling and co-morbid mental disorders;
- who need support to locate and maintain open employment; and
- who are seeking part time or full time employment in the competitive job market; and
- employers, families and communities (approached to make job opportunities available).

RATIONALE

Employment enables social connections. To work and achieve economic independence is a basic human right (Figure 5) but most people want to achieve economic goals beyond independence.

That mental illnesses are episodic and many may impact on confidence, cognition, mood, motivation, problem solving and social skills, employment is understandably disrupted.

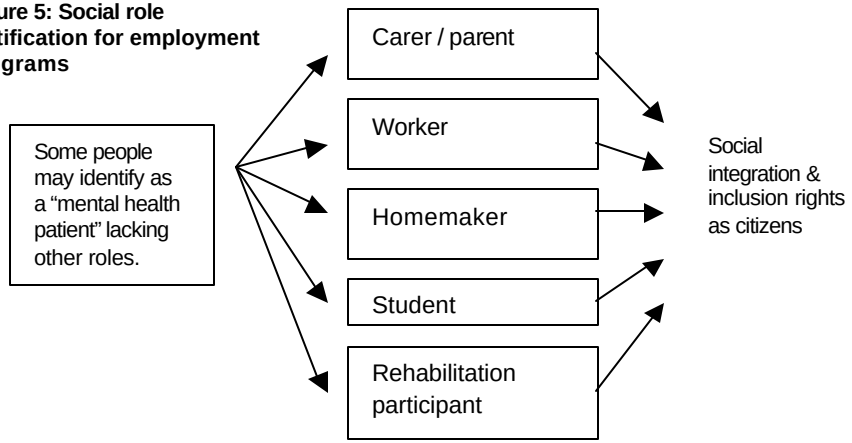
Work may be difficult to access after prolonged illness episodes. Mental illness may impact career paths and reputation. Early onset can disadvantage young people at the point of entry into training and the job market.

Employment impairment, even subtle impairment, may continue for life after symptoms resolve. [34]

BACKGROUND

NGOs have provided employment programs in NSW since at least the 1970s [10]. Some of these were sheltered and transitional employment programs within psychiatric hospitals or near to the hospital for people while in hospital and upon leaving hospital. Most were in separate buildings or on separate sites from where clinical services were delivered. There are currently at least 19 NGO open employment services and 9 supported employment services in NSW. [9]

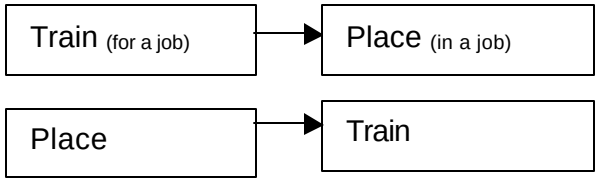
Figure 5: Social role justification for employment programs



Negative outcomes avoided:

- Welfare dependence
- Homelessness
- Illness recurrence
- Return to hospital
- Isolation
- Social exclusion
- Declining self esteem/skills
- Social networks confined to mental health system contacts only

Figure 6: Two key approaches to supported employment programs



'vocational rehabilitation' (may be called, 'supported employment' in legislation)

'open employment' or 'supported employment' in psychosocial rehabilitation international literature

Today, employment is ideally part of the thinking and practice of comprehensive mental health services. [38, 39, 49] NGOs have responded to this need — for example, non-participation in the job market is up to 78% for people with schizophrenia in Australia. [34] But employment outcomes can be hard to achieve: one study reported 16 months of employment support resulted in around 23% of employment program participants staying employed (8 hrs per week or 6 months work). [34] There is need for widespread adoption of the most intensive, evidence-based effective programs to reduce poverty and social exclusion of this group and to prevent employment disadvantage happening to newly-diagnosed young people with mental disorders.

Non-participation in the job market is up to 78% for people with schizophrenia in Australia. [34]

Example NGOs providing employment programs include Psychiatric Rehabilitation Association, Counselling And Retraining For Employment (CARE), Action Foundation, Active Employment, On Track Community Services in the Tweed Valley, Independent Community Living Association (ICLA) and Open Employment to name a few.

MODELS

The names of models that NGOs use may vary from those in the literature. The literature often refers to supported employment that in NSW is called, open employment.

- (Open) Supported Employment (also called Individual Placement and Support)

- Enhanced Supported Employment (explicit cognitive or behavioural interventions added)
- Integrated Supported Employment (enhanced + co-located clinical rehabilitation)
- Vocational Rehabilitation
- Supported Education
- Independent Employment (with low level informal follow up and ongoing engagement)
- See 'Clubhouses' separately (these include people who do not want open employment).

given the negative symptoms of schizophrenia and the concentration and motivational disability associated for a time with mood and anxiety disorders. For example, voluntary work has inherent value if undertaken in environments where it is well managed and recognised. However, here, we describe contemporary approaches only, especially those that aim to assist economic and not only occupational needs.

We currently know insufficient information about which consumers self select into NGO programs and therefore, how NGO delivered employment programs compare with those provided by NSW Health mental health services. Overall, there is a shortage of these programs and the range of programs is helpful to consumers with different needs at different stages of recovery.

'Transitional employment' or 'vocational rehabilitation' models assume stress will be reduced if a person is job ready for a role prior to placement in a job. The focus is work skills development, getting into routines for work, getting to work (public transport) and motivation for work rather than coping on the job with the job itself, and the complex social demands of open employment. It may have more application for the group (up to 18%) using NGO programs who also have an intellectual disability.

Transitional and vocational rehabilitation models have given way to open employment, which is also described in the literature as 'supported employment' or variations such as 'Individual Placement and Support'. The person re-enters employment after mental illness or relearns on the job rather than first attending programs of prolonged training. Support is either on site coaching, or on site by appointment, off site by appointment or by telephone.

Any non-exploitative, chosen occupational activity has inherent value…

our challenge in mental health is to overcome poverty, helped but not solved by overcoming symptoms. Real work for real wages is the goal.

'Supported employment' models take account of rapidly changing job markets, emphasising in vivo adaptation to job demands[2], it skips job screening if the person is reasonably qualified or suited to a role, negotiates problem solving as problems arise but provide emotional and task support. This prevents disadvantages of delayed employment due to prevocational or vocational rehabilitation training or the delays in attending transitional and less meaningful roles.

Employment is at award conditions. Income level, number of hours, duration of employment and job status are employment-related outcomes of these programs. The target for intervention may be employers and training bodies and not only the person with or having had mental illness.

Employment at award wages offered within the business contracts of an NGO enterprise is also a common model but cannot be considered open employment. However these NGOs very often informally and formally help consumers to obtain open employment though community contacts.

Independent employment is self-employment or where there is no on site support or explicit support in competitive employment roles, however, informal and add hoc contact monitors progress and if there are problems during transitions, especially to new jobs or roles. Enjoyment in life rather than job retention may be the outcome of interest.

PREFERRED PRACTICE MODELS

There is strong evidence **(II)** supporting **accelerated open supported employment** as soon as practical after the post-acute phase of illness when a person feels ready to resume work.[14, 36, 39, 40, 44] and one systematic review **(I)** reported it superior to standard hospital care, prevocational programs and Clubhouses for people in early recovery from severe mental illnesses.[50]

Some Clubhouses offer a range of models in the one organisation, from transitional employment, supported job sharing, to open employment

While most supported employment involves setting some goals and some behavioural inputs there is research support for '**enhanced supported employment'** from trials **(II). These** add explicit cognitive and or behaviour components to vocational training programs.[42, 46, 47]

Families as a source of job contacts is another way supported employment can be enhanced **(IV)**. A Sydney study of social networks in NSW Commonwealth Rehabilitation Service consumers [48], warned providers not to assume consumers lack family contacts useful for obtaining work suggestive that family interventions can be a potential ingredient of employment programs.

There is recent support for **integrated models** (enhanced + co-located clinical psychosocial rehabilitation) [37 38 39 51] **(II)**. A comprehensive range of services is provided during supported employment along with bringing together clinicians and vocational rehabilitation providers. These workers may each be located in stand alone agencies or may be located on the one site (clinical or employment program site). This kind of program can be useful for consumers who are not yet sure if they are ready for employment and the exposure to a range of services helps them opt for employment. [50]

Supported Education has not been identified as a specific NSW model used by NGOs [9] but is supported in international literature as a model of community based psychosocial rehabilitation that helps consumers reach life goals through literacy, vocational or tertiary education involvement. [52]

EVALUATIONS OF NGO PROGRAMS

The overseas literature is often not clear on the private, public or NGO status of providers. Here a careful selection was made to include positive and negative findings, but with care to ensure community based employment programs were discussed.

NSW NGOs often provide supported employment models with descriptive and outcome evaluation as part of their funding and performance agreements. There

NGOs make important contributions in an environment of scarce opportunity for consumers to access employment programs.

are many ways NGOs providing employment facilitate integration and continued contact with clinical services but studies are not published from local explicitly integrated examples. Case management may continue for consumers using supported employment programs.

Judgments about the quality of an employment program are difficult to make in any absolute sense: employment might be achieved but may be at lower levels and be less satisfactory than consumers feel eligible for. Some NGO programs are highly effective in finding opportunities in the environment in lower status jobs, while others achieve outcomes using different approaches for different consumers and can place persons in higher status jobs. Multiple outcome measures and satisfaction measures are required.

Some consumers use more than one NGO to obtain more than one part time job using support from different kinds of support programs. [34]

The above evaluations also note the importance of social relationships as the mediating factor in positive outcomes rather than necessarily how integrated a program is, or how skill-ready consumers are. At least one international study demonstrated consumers opt for more open employment over time during their membership to Clubhouses rather than remaining dependent in supported Clubhouse models. Accordingly, conclusions that supported employment is superior to Clubhouses should be made with care because it depends on what the consumer requires and prefers and the nature, comprehensiveness and how integrated the Clubhouse program is.

Even in evidence-based models deemed effective, there is need to monitor outcomes during the uptake of work by consumers. People with cognitive impairments may have increased stress from working that may require modification of the task, expectation, time frame for completion or the task. [35] Onset of depression can also be work related. There can be a trade off between employment (income, self esteem) and symptoms (distress in remaining in a job). [34]

Accelerated open employment is preferred, but not all consumers are ready or decided upon returning to work

Self-Help and Mutual Support Groups

TARGET POPULATIONS

- people wanting to protect and develop positive mental health and relationships
- people with any mental health problem (eg bereavement, stress, parenting problems)
- people with mental illness or a history of hospitalisation whose aim is to prevent relapse
- carers of those with mental illness and persons bereaved by suicide
- policy makers are targeted for policy and service development and attitude change
- community members with suspected mental disorder or subclinical conditions

RATIONALE

Peer-led self-help **groups** differ from take-home self-help provided by therapists.

Self-help and mutual support groups provide voluntary peer-to-peer group self help and mutual psychological support. They generally do not provide material, income, vocational or accommodation support. Group members share the view that those having experienced a health issue or life problem can assist themselves and others with that same problem. They form to share experiences of self-care and use of and opinions about the use of formal care services. They may link participants to formal care to a range of NGO, clinical and other human services and to community amenities.

Self-help groups are both a **pathway into care** and a **pathway from care**. Regarding the former, they play a detection role for suspected mental disorders by using the media to promote awareness of conditions and to communicate that treatments are available. Potential members may contact self-help group help lines for information prior to going to their doctor (who may later confirm the condition). Groups may provide wait list support while people access assessment services and provide contacts for tertiary health units for expert

NGOs develop low-cost public health programs of importance…

199 NGO self help and support group programs were identified in NSW in 2000, or 53% of all NGO mental health programs. This excludes telephone support and help lines. [9]

assessment. As a pathway from care, such groups are used as part of an aftercare or treatment maintenance plan (a 'treatment ally') to engage the person in ongoing positive illness management behaviours in a supportive milieu. Accordingly, self-help groups must be universally targeted across the population and across primary care (GPs) to act as a pathway into care. They must also engage with professional treatment programs so those already identified with a mental disorder can be referred to the groups. They are therefore resource intensive [53] and require ongoing communications strategies to maintain the voluntary group services year through and from year to year. The continuity they offer is described in the literature to provide a sense of community for participants who elect to use the groups long-term.

For chronic disabling conditions people may attend treatment programs and self-help groups, the latter assisting them to understand and negotiate the treatment process with assistance of other group members. Little is so far documented about who attends groups in NSW, but this is critical to their evaluation, quality development and for planning links with Area Mental Health Services.

We focus on NGOs that provide peer-led self-help and mutual support groups for coping with mental disorders, those for people bereaved by suicide and those for carers of people with mental illness. However self-help groups are widespread for all health problems, for both common and rare diseases and for health risk factors such as weight problems, fitness and general nutrition.

BACKGROUND

Support groups began in NSW in the 1950s with GROW NSW.[10] Others followed through committees of the Mental Health Association (which commenced ARAFMI, Depression and Mood Disorders Association, the Association for the Welfare of Children in Hospital, Alzheimer's and Related Disorders Association, now Alzheimer's Australia, OCD Support Groups and many others). The Schizophrenia Fellowship provides a state-wide network of groups for consumers and for carers. SOMA, Anxiety Disorder Foundation, Northern Beaches Mental Health Support Group, Club SPERANZA (for people at risk of or

…some groups aim to promote social and attitude change

bereaved by suicide) and National Association for Loss and Grief are further examples in NSW. Most groups began in the 1980s while suicide related programs began during the early 1990s. In both NSW and Victoria self-help and mutual support groups are the most common type of NGO program. [9 30 31]

MODELS

- Self help and mutual support on mental illnesses
- Self help and mutual support on mental health issues

(eg relationships, bullying at work, personal development)

- Self help and mutual support for carers/family members of people with mental illness
- Dual focus self-help groups

(eg substance use/mental illness, mental illness/suicide bereavement)

- Self help and mutual support for people bereaved by or at risk of suicide
- Groups that are discrete, unlinked to host organisations
- Groups linked with a host organisation performing wider mental health promotion roles
- NGO self-help groups that provide 'self treatment'.

Group identifications as 'mental health' or 'mental illness' or specific issue-focussed groups and group objectives may be complex and varied. They can be defined by:

- their focus (health, illness, problems, primary prevention, relapse prevention)
- who participates (who is included and excluded)
- who leads the groups (consumers, carers, professionals)
- general 'mental health' (eg GROW) or disease/problem specific (eg 'depression')
- degree of organisation (one 'group', a group network, or 'association' of groups)
- degree of autonomy from or dissent from professional programs or knowledges
- activities and objectives further to the conduct of groups

Many typologies have been offered to distinguish 'self-help' from 'mutual support'. Other typologies take these two functions together and offer alternative categories. One study offers 'unaffiliated', 'federated', 'affiliated', 'hybrid' and 'managed' as distinguishing types. [59]

when there is a 3 month wait to see a psychiatrist a self-help group is a life line

the public health importance of self-help groups is in influencing attitudes, health behaviour, caring for others, and promoting policy discussion …

Groups that have professionals facilitating the group meeting, rather than providing support or administering the amenities the group uses, are not considered 'self-help' groups, unless the professional is a guest speaker only or identifies as a consumer. Group leadership remains with consumers. A sizable literature points to the need to educate professionals to switch from being a provider to a partner to support rather than conduct self-help groups. (An exception is 'self treatment' groups below).

Groups generally do not claim to treat mental disorders but help people access, understand and use treatment well. Groups vary in their philosophical positions on the role of treatment.

Groups with an illness or disability self-management approach aim to improve coping. Some are structured (eg AA, GROW) with strong self-responsibility and personal change objectives while others are less structured or entirely unstructured. They still share information for and encourage illness management but without implying that participants are responsible for the illness and reject negative stereotypes and portrayals of those with mental illness. Their emphasis may be mutual support and social rather than self change. Some ensures the group finds its own direction with empowerment and community development approaches which may extend to general socialising, telephone and website support.

Some self-help groups are in fact, large membership associations, the association acting as a host organisation for the groups and providing an infrastructure for the development of more and more groups (Figure 6). Others are auspiced by a NGO with multiple functions. Some host organisations may foster the community development of new self-help programs, new groups and new associations and these tend to have active public policy advocacy roles. NGO clearinghouses and 'liaison institutions' (eg a sponsoring hospital or specialist clinical unit) are also described in the literature. [66]

Many NSW groups appear to use recovery principles as understood by mental

…that they critique assumptions in policy, or of professionals, adds value.

health not alcohol and other drug programs. Many have been active promoting recovery oriented and consumer-led mental health services. This has been in the context of the group's role in linking consumers to evidence-based prevention programs and clinical treatments for mental disorders and at the same time, advocating service improvement, of which active consumer participation is part.

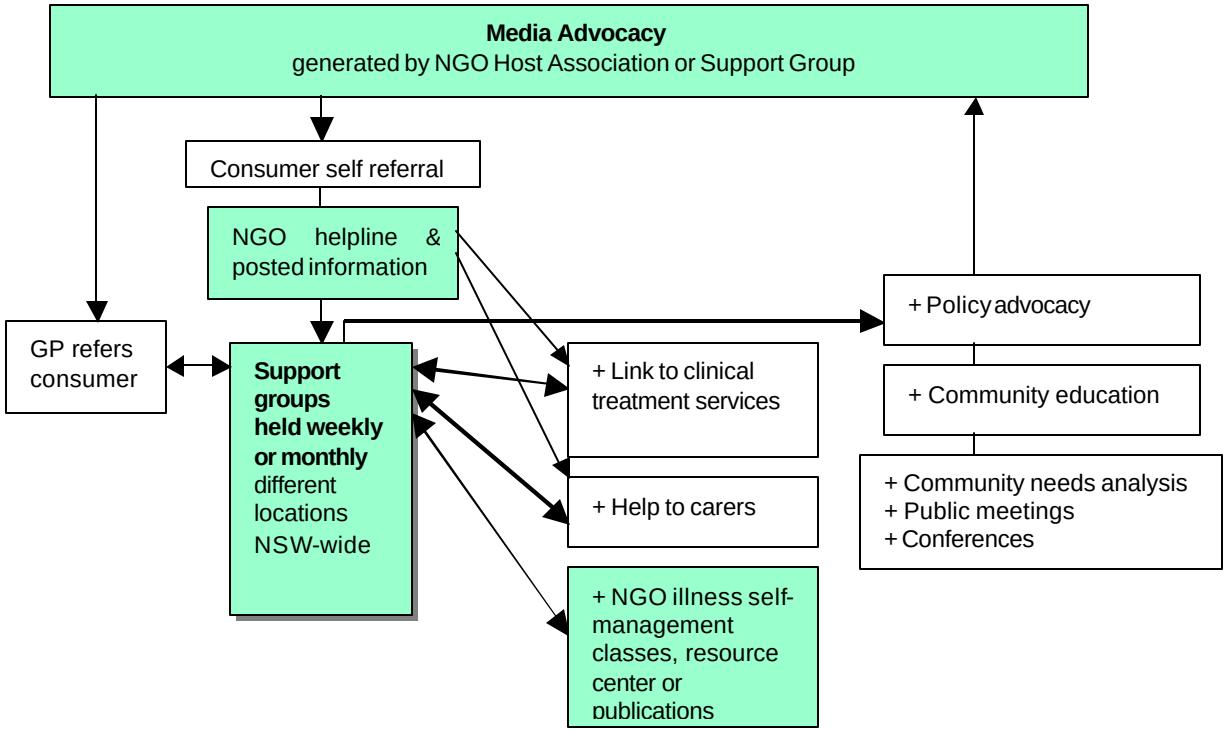
The recovery orientation of groups is also evidenced by a number of groups running funded formal (professional and consumer-staffed) telephone information and referral services aiming to overcome barriers to accessing treatment. Larger NGOs of self-help groups are also publishers and clearinghouses of treatment and self-help information. They have often been partners in researching and preparing literature printed by NSW Health as treatment booklets for consumers. NSW NGO self-help groups have also produced evidence-based clinical practice guidelines. However, support groups include information that is easy to read for consumers, question and expose discriminatory assumptions of professionals or the media and probe into areas where consumers need more of their questions answered or research demystified.

Groups may conduct special events, host or link members to additional activities (Figure 7):

- self-help group and NGO-provided psychoeducation
- community education meetings, public meetings or conferences
- mental health days, theme weeks, media conferences and awareness campaigns
- family interventions
- skills development
- published information

We discuss some of these 'ingredients' separately as 'other psychosocial programs'.

Figure 7: Support groups within a host association that takes a public health / community development approach to fostering support groups



Negative outcomes avoided
(depending on group type and focus)

- Delayed entry to treatment
- Sub-optimal treatment engagement
- Re-hospitalisation
- Poor use or premature stop to medication use
- Social isolation
- Limited social networks
- Low community mental health literacy

PREFERRED PRACTICE MODELS

Consumers must be free to self-select into groups they find preferable and can identify with.

Entry and exit to groups is not well-understood or documented in NSW. Some consumers may regularly use a self-help host agency (its library, help line or website) but not always attend groups, so evaluation is complex. There is debate in the literature as to the extent to which the populations using self-help groups differ from those using clinical treatment services. Different group philosophies attract different populations. The attitudes of referring professionals are a factor in who accesses support groups.

Some NGO self-help programs take a **broad public health multi-service approach** as shown in Figure 6 using community work, media advocacy, social marketing, community development, education, information dissemination and other tools of health promotion. In NSW, the Mental Health Association (including the Depression and Mood Disorder Association), ARAFMI, Schizophrenia Fellowship and Club SPERANZA use this or variations of this approach. The shaded boxes show where program infrastructure is needed as opposed to activity undertaken. Host associations provide this infrastructure to groups. These are complex to evaluate since attribution to component parts of the program is difficult.

'**Self treatment' models of self-help groups require explanation** as a newer form of self-help group because they reflect collaboration with formal treatment services. Much literature is devoted to therapist-developed 'self-help' manuals using 'bibliotherapy' (take home self-help reading) and manualised evidence-based treatments. This new generation 'self help' departs from original notions of organic or pure consumer self help ('how I helped myself') and on their own, these are not self-help *groups* or groups at all. Their idea is for more people to access these formal treatments if they are provided in a do-it-yourself format that retains the structured self-exposure with guidance from the therapist at a distance.

Peer-led groups for carers can assist outcomes for people with schizophrenia [58]

In NSW the NGO program, Triumph Over Phobias, is an example of a self-help group adopting an internationally tested 'self-treatment'. That it is promoted through a group modality through an existing self help group program for people with anxiety disorders, meets criteria for 'self-help or a self-treatment' group. This is a significant departure from other self-help groups that are an adjunct to treatment, not treatment in their own right. Professionals viewing self-help groups as a vehicle for the dissemination of evidence-based treatments is a sound public health strategy, if agreeable to consumers, and need not detract consumers' attention from social change, social critique and broader advocacy objectives.

Given that relatively few people with mental illness use public mental health services, self-help groups provide an option across populations, both those with severe illness in maintenance phase of treatment and those with less illness severityand partners, family and friends.

EVALUATIONS OF NGO PROGRAMS

There is a vast social support literature, a sizable literature describing self-help groups, but few evaluating mental health self-help and support groups in the Australian context. Available older research commends self-help and mutual support groups and telephone support as helpful psychosocial programs that should be supported[2] **(IV, V)**. The World Health Organisation and more recent studies confirm their value. The number and sustainability of groups suggests they are greatly relied upon in NSW.

Needs assessments in NSW report these programs are under-resourced and are mal-distributed across the State[9 53] because their development has relied upon voluntary effort (true to self-help) with inadequate host support or funded planned approaches.

We found no published evaluative studies of NSW NGO self-help or mutual support groups for mental illness, suicide prevention groups and bereaved by

What works is building a sense of autonomy — people taking decisions about their care and about helping others [59]

suicide groups.

In the literature, at least 8 evaluations exist for GROW but these are small and now dated. In the 1990s research following up a small number (n=39) of US GROW members found reduced hospitalisation rates in those attending groups [54] and GROW in Western Australia is now described through a PhD theses. [55] A reduced hospitalisation rate was also found (from 80% to 33%) in a larger study of mood disorder DMDA participants in the US (NSW DMDA modelled itself on the same approach for mood disorder self-help groups in NSW) **(II).** [56] Long-term participants who were former hospital patients had symptoms no greater than the general population, and the more involved the members and the longer their involvement, the better their mental health **(IV).** [57]

In Hong Kong, an RCT evaluated a **peer-led carer mutual support** group over 12 weeks for 96 **families of those with schizophrenia** comparing groups to standard care and professional-led family psychoeducation groups. Carer mutual support groups were superior impacting on patient functioning, reducing re-hospitalisation and improved stable use of mental health services without those with schizophrenia increasing their use of mental health services **(II)**. [58]

There is moderate evidence from a systematic review **(I)** that family interventions may reduce relapse and help patients take medication. A study of long-term users of self-help groups found that it was the meaning in helping others and the organisational culture of enabling people to take decisions for themselves and others that produced positive outcomes. [59] The US Alliance for the Mentally Ill group participants reported that receiving information and long term attendance were the most valued elements **(V)**. [60] A two-year follow-up of a self-help group for carers of men with schizophrenia reported those patients with higher expressed emotion (EE) had relatives more likely to join the group. The group improved EE in the patients when compared with a control group of patients with the same illness. Relatives in the group of high EE patients did not reduce their own EE, but their social networks, perceptions of their health and other outcomes improved. [61]

Peer support is a robust evidence-based NGO program for children and young people.

Peer support, other than in groups, is an emerging model in consumer-led /peer-led programs. [96]

Dual focus 12-step groups for people with substance use and mental illness have been evaluated showing group attendance and adherence to psychiatric medication were associated. [62] The value of groups for people with pre-clinical symptoms as well as for recovery has been reported for **anorexia and bulimia nervosa** in a review of groups in USA, Austria and Czechoslovakia **(V).**[63]

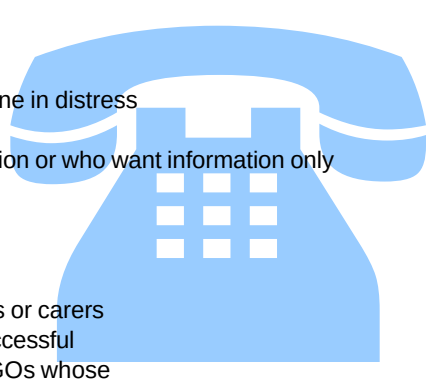
Recent Royal Australian and New Zealand College of Psychiatry evidence-based clinical practice guidelines (2003) support self-help groups for anxiety, panic and agoraphobia, schizophrenia, depression and anorexia nervosa. Few studies on self-help were included but these guides synthesise expert, research and consumer opinion.

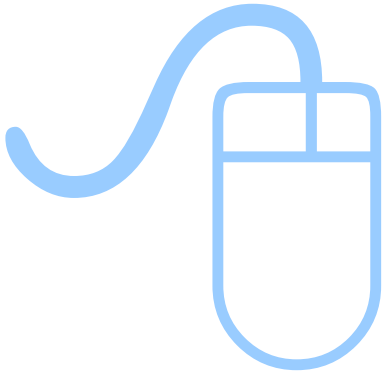
Less is known about groups for people who self-harm. Mental illness is an individual and family risk factor for suicide, which suggests that support groups for those with major mental disorders may reduce some of this risk and may engage people with potential helpers. However data were not found precisely on this aspect of self-help groups. [64]

Groups can reduce distress in young people bereaved by suicide in a parent or sibling immediately and at follow-up [65] but poorly targeted interventions in schools have been known to impact negatively on some students. [64] **Peer support** is a mutual support model for children and adolescents in buddy and group formats and is a robust evidence-based, primary prevention, universally-delivered NGO program.

More evaluations of the diverse mutual support and self-help programs across the lifespan and delivered by NGOs in NSW, are now indicated.

Help lines, Information Services and Websites





TARGET POPULATIONS

- people experiencing problems, distress or concern for someone in distress
- people who may not use a face-to-face mental health service
- people unsure if their problem warrants professional intervention or who want information only
- people in crisis

RATIONALE

Help lines run by mental health professionals and/or run by consumers or carers or a mix of staffing, have been introduced above as an ingredient of successful self-help group programs. Here we introduce the program logic for NGOs whose sole focus is excellence in providing help lines or website services for the dissemination of information or for the provision of telephone counselling, crisis counselling or support. Counselling services are also called, 'telecounselling'. Help lines and websites are usually national or state-wide. [71]

Telephone services are viewed as a low-cost way to enable at least minimal access to a mental health service. They require sound database development for referral information. The service may provide initial or ongoing telephone help. It may focus on specialist information and referral, or counselling, or both. Some identify as 'primary care' as Lifeline does [70] while other help lines may have a specialist knowledge or focus linked with education, self-help groups and publications eg NSW-wide Mental Health Information and Referral Service of the Mental Health Association. 'Dympna House, (information and counselling for incest survival) is another specialist example.

Research shows that men who are unlikely to use mental health services may use a help line instead.

BACKGROUND

A glance at a service directory in NSW or at the front pages of the telephone book indicates around 70 help lines in NSW. Of the Mental Health Coordinating Council's members, 18 programs were identified (or 5% of all NGO mental health programs) as providers of help lines. A Commonwealth Government review identified 131 non-government organisations providing 'telecounselling' services nationally in 2002, of which 42 are provided by Lifeline. [71] The first Australian Lifeline Centre was opened in NSW in the 1960s. The Mental Health Information and Referral Service specialises in mental health and was a key recommendation of the NSW Government's Richmond Report to better integrate community mental health services and access. More recently, some NSW Health Area Mental Health Services began to provide 24-hour help line access to general information and referral at a regional level.

MODELS

- Telephone Information and Referral Services
- Telephone Counselling
- Telephone Counselling with Follow-up Appointment
- Telephone Consumer and Carer Support (see self help groups)
- Website-delivered help and referral

The qualifications and skills of telephone information providers or counsellors is a key issue distinguishing models. Other than Lifeline Centres, few programs claim to be 'crisis lines'. Nonetheless, help lines have been shown to attract high-risk callers with suicide rates 2.5 to 10 times that of the general population and the extent to which they might help prevent suicide at individual and population levels has been widely debated. [68] The national review reported that between 62 and 90% of calls are not answered due to lack of resources to these programs. [71]

people phone to talk about loneliness and relationships…related to or complicated by their mental health condition.[70]

PREFERRED PRACTICE MODELS

Excellence is required in the infrastructure, technology and staffing enabling phones to be answered, [71] the quality of information provided, how the information is delivered, how quickly the information is provided, the currency and appropriateness of the referral contact and, if counselling is provided, it must be skilled, brief and appropriate. Volunteer-run help lines frequently require trainee, graduate or retired health professionals to staff telephones. Consumers and carers are well placed (if supported) to provide telephone-based mutual support and some information services subject to training and the role of the agency, but we found no evaluations of them performing in these specific roles.

EVALUATIONS OF NGO PROGRAMS

NGOs report the outcomes of their services to community donors and members in their Annual Reports and websites and in funding and performance agreement reports to their funding bodies.

The Commonwealth's review in 2002 found no relevant randomised controlled trials to test the efficacy of telecounselling and website services, but some report its positive role as an adjunct to clinical mental health programs. We do not know the extent to which these programs impact different groups with different needs. They may reduce stress, promote entry to professional help, prevent the worsening of mental disorders, and reduce risk for suicide, but help lines have community support for providing a low-cost entry point to mental health and welfare services. [64]

The National Youth Suicide Prevention Strategy funded increased capacity to two national help lines, Kids Help Line and Lifeline Australia while also assisting website databases to be further developed and shared. Subsequent effort under the LIFE Framework and the National Mental Health Strategy further consolidated and evaluated these services. [67]

More recently, a NSW evaluation of the Shoalhaven Lifeline Centre reported that

40% callers are repeat callers and two thirds are not receiving any mental health services. Callers have high levels of distress, and symptoms suggestive of mental disorders, high levels of reported disability, suicidal thoughts and behaviour. The evaluation used the K10 to measure symptoms callers disclosed. It showed that 72% of callers scored very high, compared with 3.6% of general population. Callers were 3 to 6 times more likely to suffer psychotic symptoms, 7 to 13 times higher rates of depression in the past 4 weeks and, 29% had had thoughts of self-harm currently.[69]

Website and email networks are rarely State-based but the national review found help lines were usually state or regional, rather than national [71] and few have been formally evaluated. [67]

In commenting on the review, the CEOs of Sane Australia and Lifeline Australia with another author concluded that new directions were threefold:

1) we can integrate help lines with mental health services more,
2) we can improve mental health care within help line frameworks including matching phone help with internet therapy and psychoeducation and
3) fee-based web counselling with specialists and non-specialists may have a role but evaluating all models was vital. [72]

In NSW there remains rich opportunity for evaluative work in a State with the most help lines and the longest history of very diverse help line and website mental health programs.

Attitude Change and Awareness Campaigns

TARGET POPULATIONS

- mass media professionals and populations
- mental health professionals
- selected and indicated groups at risk and agencies in contact with them

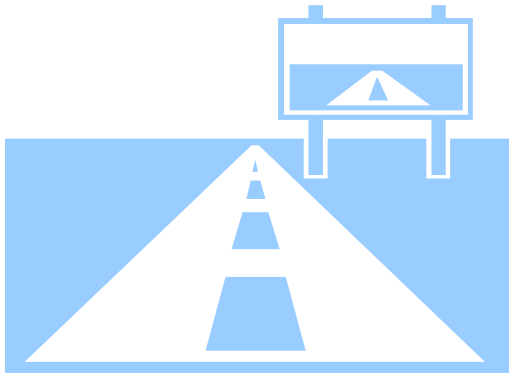
RATIONALE

Attitude change and awareness campaigns are planned mental health promotion activities where print and electronic media are used to reach target audiences with priority messages. While most NGOs use mass media to inform community members of their work, here we focus on the more strategic use of media for major communications programs intended for social and health change.

Such campaigns are run as collaborations between community organisations using a common theme, or they are run in association with government support and invite wider community involvement. Some are run year-through by a single organisation using specific media advocacy strategies. While raising awareness is a health promotion staple, attitude change and awareness campaigns in complex fields demand high levels of resources and expertise to be effective.

BACKGROUND

Theme weeks by mental health NGOs began in the early 1970s with National Mental Health Week of the state and national Mental Health Associations. Others followed bolstered by the success and spread of self-help groups and wider NGO engagements. Such programs are vital to mobilising the resources and good will of local communities. They may also aim to raise funds and recruit



From 1991 to1996 billboard posters at major Sydney railway stations gave year-through positive mental health messages … being millions of dollars of donated advertising …[73]

volunteers or issue-based support that can benefit all NGO mental health programs.

MODELS

- Health Days eg ‘Stress Less Day’, ‘World Mental Health Day’
- Health Weeks eg ‘Schizophrenia Awareness Week’, ‘National Mental Health Week’
- Anti Discrimination and Anti-Stigma Awareness
- Multi-component strategies linked with community education
- Suicide Prevention Gatekeeper Training

We can only introduce some NGO approaches here since each approach involves a multitude of communication techniques and considerations. Much has been documented on suicide prevention approaches elsewhere so gatekeeper training will only be introduced here. [67] **Gatekeeper training** qualifies as an ‘awareness’ program albeit that it also involves community education and training since the model universally targets communications in a geographic area from which adult community members are recruited and trained to detect those at risk for suicide. Gatekeepers then intervene appropriately and encourage the person to seek assessment and help. The focus of training is symptom and risk awareness. These programs were first developed overseas and have been refined for use in Australia. Some were evaluated under the National Youth Suicide Prevention Strategy and the LIFE Framework. [67]

Theme Days and Weeks are also universally targeted. They may additionally involve selected and indicated target groups with an interest in mental health. Some may target mental health professionals or welfare agencies and elicit their support and involvement to optimise the reach and impact of the theme message. These programs select a time in the year each year to target mass media with communications for directing to populations. NGOs seek to influence the scripts of television programs eg a breakfast show or television series may feature a mental health story. Billboard posters, posters for clinics, libraries, churches, schools or shops, merchandising and events at local venues supplement electronic media messages.

Health information becomes health behavior change when filtered through local groups and community…where discussion takes place between persons, norms are challenged and new norms can be nurtured

Some organisations adopt the same theme for use over repeated years. After the Day or Week ends, messages may continue year-through giving focus to other public events. They are important mechanisms for uniting and focussing effort in voluntary associations, articulating common values.

The target knowledge and behaviours NGOs seek to influence vary but may include:

- identifying problem behaviours that pose risks to mental health (bullying, violence, sexual abuse)
- promoting protective behaviours for good mental health (walking, positive parenting, 'stress less')
- recognition of mental health problems and disorders
- when, how and where to seek help and what to expect
- evidence-based treatments for mental disorders
- recognising risks for suicide and responding after suicide
- NGOs promote values of compassion and response to those in distress
- NGOs develop anti stigma messages and address discrimination against those with mental illness

Program designs are informed by public health and social sciences (communications sciences, dissemination sciences, sociology, social psychology, education and marketing) having a substantial evidence base for conducting these programs to effect. But they must be large-scale campaigns or large public events to capture public attention. They must also be localised to engage people face-to-face *and* be sustained after pilot programs demonstrate safety of the message. Governments participate by funding NGOs to increase the scale of their efforts, by hosting joint programs, or funding their own major communications strategies.

Governments first undertook major national **anti-discrimination and mental illness awareness** campaigns under the then $8M Community Awareness Program of the first National Mental Health Strategy in 1994. Prior to this, NGOs undertook this work in NSW for two decades.

The LIFE Framework also funded communications strategies, being explicit

EXAMPLES

"Walk for Life", and "Cycle for Life" (around Australia) — Suicide Prevention Australia Inc 2003, 2004

"LifeForce Annual Suicide Prevention Memorial Service" Sydney Opera House **—** Wesley Mission, commenced 1995

"Reclaim the Night" anti sexual assault campaign **—** Womens movement non government organisations

"Stress Less Day" — Mental Health Association of NSW, campaign commenced 1995, continues each Mental Health Week

"National Mental Health Week" — commenced 1974 by Australian National Association for Mental Health and State Associations **uses International Year themes**

Schizophrenia Awareness Week — hosts events, conferences and art exhibitions in May each year since 1985

Mental Illness Education Australia (NSW) provides classroom-based education to teach compassion about mental illness and it supports mental health in school curricula.

"Yellow Ribbon" — suicide prevention program that communicates to young people that it is OK to ask for help

knowledge dissemination strategies. The aim was to share safe approaches to suicide prevention with professionals and community leaders through websites and manualised programs that could be adopted for use in local communities. Successive suicide strategies also funded positive parenting, carried out by community organisations through classes, mass-reach print media and school-based interventions. [67] Funds also supported NGO-run conferences to ensure less favourable interventions were discouraged for the uptake of evidence-based approaches. Some NGOs have promoted communication strategies to help young people at risk for suicide ask for help by using billboard posters and materials disseminated through shops and banks. Sensitive messages of this kind require a concurrent commitment to evaluation.

Further government investment for community attitude change followed under the National Depression Initiative, 'beyondblue'. However, large-scale government initiatives still require local NGO involvement to reach their intended audience in ways that the information can be digested. Associations in the mental health field continue to work at local and state-wide levels **year-through** to produce posters, stickers, free-to-air community radio and television commercials and they engage media personalities and pro-bono advertising agencies in their work to bring priority health messages to local communities.

Other examples of **attitude change** work by NGOs include sustained pressure on media reporting standards and addressing discrimination in employment and public policy. Mental Illness Education Australia Inc has undertaken classroom based attitude change over the past fifteen years. Their staff and volunteers bring messengers about mental illness, people with mental illness, into the experience of students directly. Evidence suggests that it is the direct positive experience of people with mental illness that fosters positive attitudes.

In summary, NGOs both produce communications strategies and are important for the uptake of information at local community levels of communications generated by themselves and by others. NGOs are partners with governments in the design and delivery of messages for use in mass media. NGOs are positioned to sustain such messages by local actions.

NGOs promote particular health values in society. They promote human rights and humanitarian sentiment, give messages of support and inclusion to those feeling on the margins, they create practical opportunities for inclusion, and through mass reach communications and local uptake of those messages, provide the ‘glue’ we call social capital in society.

Centre-based support, work, education and leisure

TARGET POPULATION

- people with psychotic disorders, other disabling and/or comorbid mental disorders
- who want to socialise and develop skills
- who may want to undertake meaningful work, including on a shared basis
- and may not be ready to, be undecided about, or may not want to re-enter full time employment

RATIONALE

There need be no explicit rationale for people to come together to socialise. However people in recovery from major mental illness recognise that some form of social activity is critical for learning to reconnect with others. In particular, people in recovery from psychotic disorders generally find it is necessary to have ways for structuring the day. The 'work ordered day' is a key concept within the Clubhouse model of centre-based programming. Such a structuring mechanism may not be available if the person is living independently in sole occupant housing and without access to or readiness for employment.

This chapter groups together programs that have in common the coming together in a communal place or 'centre' rather than being done in a person's home or in a clinical mental health service.

The program objectives can be leisure, keeping company with others, work, illness management skills, adult education, social skills or living skills or a combination of these. Centres and Clubhouses may include a diverse mix of consumer-led and professionally-provided psychosocial rehabilitation and recovery programs. They may also promote a sense of belonging.

The move to community meant nowhere to go during the day for people unable, undecided about, or not ready to return to work.

BACKGROUND

To some degree, for formerly hospitalised people with mental illness, centres and Clubhouses take the place ofthe activities once provided in hospital 'Day Programs' but with the shift to consumer self determination about what activity is on offer and engaged with. NSW Health Mental Health Services also once provided 'living skills centres' where community clients without employment attended. Few of the latter now exist with the pressures on NSW Mental Health Services in providing crisis and mobile acute care.

The Schizophrenia Fellowship of NSW refers to Clubhouses as a 'partnership between members and staff and a place shared by everyone, but members' contributions are voluntary and are not bound by formal contracts'. The 'work ordered day' is central to Clubhouse programs run by the Fellowship. [75]

MODELS

- Clubhouses (multi-component programs of social, vocational and other skills)
- Other Centre-based work education and leisure
- Formal psychosocial rehabilitation with sessional or employed staff

Some centres provide formal psychosocial rehabilitation delivered by their on-site professionals while others are unstructured 'drop in' centres or may describe themselves as 'consumer recovery programs'. Clubhouses may blend both approaches using structured and unstructured approaches so long as the consumer elects to participate.

In structured programs consumers with professional qualifications or rehabilitation staff may provide psychosocial rehabilitation. Some structured programs may have links with additional staff, such as an on-site doctor or sessional visits by clinical mental health services or adult educators providing classes. The programs aim for structured psychosocial objectives to be met.

In some unstructured settings, while the objective is not to provide 'psychosocial

Some analysts view clubhouses as 'ghettoes for the mentally ill'. This view is plainly wrong. It is stigmatizing and discriminatory. People with mental illness are from all walks of life and have the right to socialise however they wish and with whomever they wish.

rehabilitation' a range of psychosocial inputs are nonetheless organised to facilitate stimulation and enjoyable activity. In both approaches visitors may provide sessional activity (musicians, educators, chefs, artists etc) but are drawn from a wide resource base of the community rather than mental health clinicians.

Some centres and Clubhouses aim to achieve economic and cooperative enterprises between members and some Clubhouses have stepped leisure-to-employment programs.

The Pioneer Clubhouse at Balgowlah in Northern Sydney of the Schizophrenia Fellowship demonstrates the range of activity undertaken: Its work units include:

- Food Services Unit (menu planning, budgeting, shopping, meal preparation)
- Communications Unit (computer operation, reception, photocopying, newsletters, statistics)
- Employment Unit
- Advocacy for employment and housing. [75]

PREFERRED PRACTICE MODELS

NGO-run programs increasingly prefer consumer-guided or consumer led programs, or at least partnership models with consumers **(V)**. The Clubhouse format has international [2] and local consumer support [76][77] but other centre-based programs that are similar, but do not adopt the name of 'clubhouse', also have support. The research (limited here to searches regarding outcomes for schizophrenia) suggests benefits from consumer and peer-to-peer models and from environments of empowerment.

However research also suggests **benefits in structured approaches** with outcomes increasing with enhanced structure and hours of exposure, especially for people with severe disability. The point becomes, what consumers feel ready and able to engage with and what they require to meet their recovery goals.

Over 45 years of experience, 400 clubhouses world wide in 24 countries. [75]

Because the elements of interventions vary so greatly, an overview of the available evidence will be given.

In general terms, psychosocial rehabilitation programs achieve outcomes for people with severe mental illness, including in community settings and across cultural groups.[2 78 79] Centre-based psychosocial rehabilitation improves health outcomes but at **intensive levels** for people with a history of hospitalisation with effectiveness shown for programs of 5-day per week intensity and with leisure contact on weekends[80]. This suggests that well-resourced and structured models are needed but consumer-centred goals should be paramount.

'**Life skills'** programs (group or individual) aim to enhance social, personal and domestic functioning especially managing money and households. A Cochrane systematic review included only 2 controlled trials of 129 citations and concluded that there is no evidence that life skills training helps people to acquire domestic skills as such. **(I)** [81]Centres in NSW do not focus around this objective alone. (The 'life skills' model that has proven effectiveness in the literature is that relating to the primary prevention of substance misuse amongst young people).

Supported education has been evaluated. [82]It aims to assist people reach life or employment goals. Due to medications enabling better cognitive functioning these programs assist people to achieve literacy, TAFE or tertiary education, some support for which can be offered in centre-based formats.

Psychoeducation and illness-self management can be delivered in peer-to-peer formats, in centres and individually and by rehabilitation health professionals. They aim to help consumers maximise their knowledge and control of their illness, treatments, and to recognise warning signs for relapse. Illness-self management underpins much of the content in self-help groups and group-based psychoeducation can be done within centre-based support programs. NGOs may not use the term, 'psychoeducation' and may adopt simpler less medical terms like, 'community education' or 'information giving'.

13 centre-based support programs and Clubhouses operate in NSW by community organisations for people in recovery from mental disorders.

Psychoeducation can reduce recurrence of bipolar disorder **(II)** [83], can aid insight for those with schizophrenia, but has not yet been shown to reduce suicidality **(II)** [84]. It can aid the continuous use of medications [85 86] and improve wellbeing [85] **(I, II)** compared with standard care. When aimed at families, psychoeducation can assist outcomes for those with schizophrenia including reduced relapse and hospitalisation.[86] One RCT of peer-to-peer counselling after psychoeducation reported no difference in hospitalisation rates or compliance but better use of medication as prescribed **(II).** [87] However, recent research **(I)** reports more structured 'compliance therapy' or more direct cognitive interventions are more effective than non-specific counselling or psychoeducation to reduce medication use problems. [86] The research on skills training, including social skills, vocational skills, life skills and illness management skills is that the skill taught must be transferred into everyday life aided by in-vivo individual consultation. [88] This implies that NGOs should consider employing or contracting rehabilitation professionals with cognitive therapy and behavioural training skills to optimise the outcomes of these group-based programs.

Creative **arts programs** often feature in centre-based psychosocial support programs and have been evaluated **(I)** as an adjunctive treatment approach for schizophrenia. Sixty-one studies were identified on 'art therapy' (the use of arts materials for self-expression and reflection in the presence of an a trained art therapist) but trials were small and inconclusive. [90]

Family interventions are effective. There is robust evidence that psychoeducationally and behaviourally oriented help to families improves outcomes for people with schizophrenia, the latter being less likely to relapse (see 'self help group chapter). [91]

Clubhouses have been examined in the international literature and they may contain any number of the above approaches along with their work programs and leisure activities. Evaluations have mostly compared them with open employment programs even though the populations of Clubhouses have been shown to be considerably different to consumers using supported employment programs other than Clubhouse models. For example, international research

Both structured and unstructured programs have value. Consumers engage with what meets need at different stages of recovery

shows that people often select a Clubhouse when they do not know if they are ready for open employment but do move toward employment objectives in time.

As for their impacts on social, skills, quality of life, rehospitalisation and other outcomes, Clubhouse evaluations must tease apart the aspects of their multi-component interventions. Evaluations have been interested in the interventions themselves and aspects of organisational culture or environment especially on the communication of social support and the ideas around 'belonging'.

Participants attending Clubhouses have been found in a US study to be more likely to continue their oral medications than matched non-participants taking medication alone, the conclusion being that Clubhouse culture promotes medication adherence **(II).** [79]

A number of evaluations report that consumers value support from each other, at times more so than staff support, [91] a principle underlying the Clubhouse model which values all members, but especially gives valued status to peer-to-peer support.

The first Clubhouse in Turkey administered 4 health outcome tools over 8 months to see if non-professionals could achieve health gains for participants in activities run by volunteers and participant relatives. The Clubhouse was coordinated by a volunteer psychologist and conducted programs one day per week that achieved health gains on all measures. This suggests that non-intensive participation can still achieve important health outcomes or else is suggestive that Clubhouses attract a range of participants with diverse needs, some with lower levels of illness or disability severity **(IV)** .[92]

One study undertook multiple-site evaluations of 22 of a US State's 24 psychosocial programs in a state-wide inventory to see if programmatic mechanisms were at play within Clubhouses, or if it was that there was a service available in general that achieved individual outcomes. It hypothesised that Clubhouse services were positively related to social environment and the high psychosocial functioning of participants (that is, that social environment

I went back to my job too soon. I was still sick and people noticed. I stayed sick much longer… 10 years on I worry that I have forever ruined my professional reputation by an early return to work…

mediated relationships between program components and member functioning and the high social functioning of participants enabled the culture and environment to be positive). Programs varied by Clubhouse focus, psychoeducation focus and recreation focus.

The Clubhouse hypothesis was not supported: “results of effective programs were social, vocational and educational programming with strong psychoeducational components. Skill building groups, educational and supported employment programs and adult education support services were positively related to functioning variables of individuals particularly, self esteem and hope. Positive findings were found between consumer-managed, community-based and self-help activities and aspects of social functioning. Educational rehabilitation services may work by engendering mutually empowering social environments, thereby increasing member feelings of hopefulness”. This suggests support for structured and educative environments that foster hope (the latter advocated by ‘recovery’ advocates) but with traditional structured psychosocial rehabilitation components on offer to enhance self-esteem and psychological functioning. When this takes place within a Clubhouse, there are multiple benefits for participants. [93] The study articulates the internal recovery mechanisms for consumers that can be shaped by the external resources of good psychosocial rehabilitation.

A systematic review [50] evaluated a diverse range of day programs seeking to establish the effectiveness of ‘day care’ for people with current severe mental disorders versus active individualised treatment such as case management for a range of outcomes. It had three research comparisons: 1) acute day hospital vs hospital admission, 2) various models of vocational rehabilitation as to which ones enabled open employment; and 3) day hospital/day centres versus outpatient care. In the third question, 5 studies compared the use of ‘day hospital’ and ‘day centres’ vs outpatient (professionally delivered) community care, such as case management. Of these, 2 of the 5 studies found individual treatment programs were superior to day care centres. Regarding the second research questions comparing models of vocational rehabilitation, as noted in the Employment Chapter, accelerated employment rather than Clubhouses was

superior if the outcome of interest is participation in the open job market. **(I)**

Economic evaluations have been undertaken on the reorganising of services where there is legislation or agreement about which sector provides which type of mental health service. [94] In 1998, Polish services were reconfigured to include a new system of 'social welfare services' for psychosocial rehabilitation in addition to 'clinical mental health services': new social welfare-run components were vocational rehabilitation centres (VRC), community centres of mutual help (CCOMH) and specialised social help services at clients' homes (SSHS). These reflect broadly, the models performed by NSW NGOs in psychosocial rehabilitation. Economic evaluation showed new costs associated. However the new social welfare services reduced hospitalisation and partial hospitalisation and overall costs to the mental health system reduced. Daily social support was emphasised in the new system of care. [94]

EVALUATIONS OF NGO PROGRAMS

We found no published controlled trials of NSW or Australian NGO centre-based programs for adults in recovery from major mental disorders.

NSW Health Centre for Mental Health commissioned a review of Clubhouses in NSW but the report is not yet in the public domain.

Descriptive local evaluations also exist. The Schizophrenia Fellowship commissioned an independent initial descriptive evaluation that interviewed members and staff about their Clubhouse [76]. The programs reportedly gave meaning to participants. They offered security, recovery, acceptance and the hectic pace of the centre translated into a perception by consumers that there were 'issues requiring actions' in everyday reality. The 'work ordered day' provided structure and rehearsal for roles elsewhere at a consumer's own pace. In short, the centre mobilised activity. Centres experienced some staff pressures and turnover found in international Clubhouses. **(V)** Another service description stated that the successful features of the model are:

A safe place

A place I am accepted

A place to regain dignity

A place for contact with others

Transitional employment

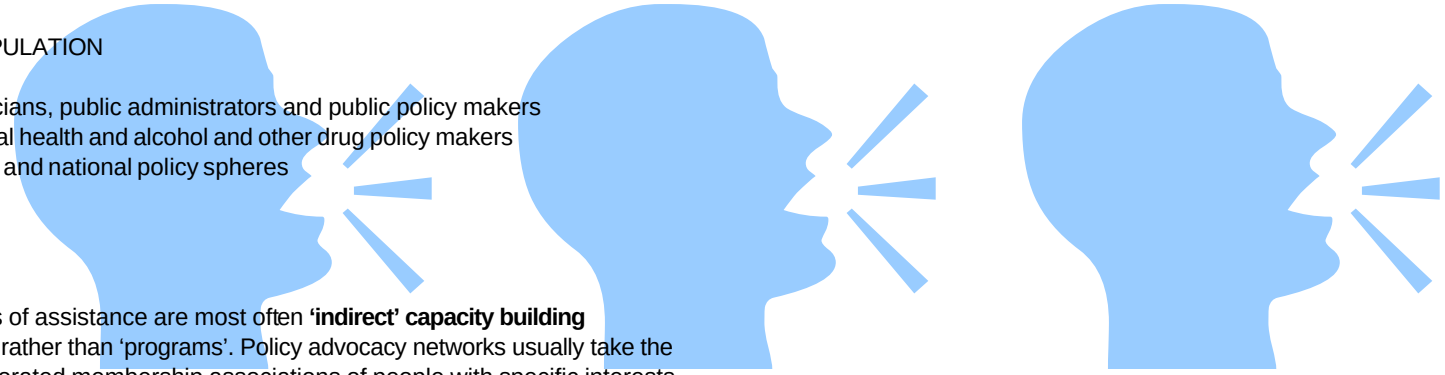
Open employment [76]

- Empowerment
- Consumer member participation
- Wellness model
- Holistic approach to recovery
- Clubhouse culture (environment that stands for certain values, natural social learning)
- Democratic model of organisation. [77]

In conclusion, there is a clear place for centre-based programs other than employment programs especially those with graduated opportunities from leisure to work and from shared and supported work to independent job market participation as consumer needs change over time. The degree of structure and the goals that are the focus of an intervention in these centres and Clubhouses can be guided by consumers. This can be done through consumer participation in the staffing and management of Centres and can also be achieved through structured needs assessment and health outcome monitoring, so consumers can opt for the approach appropriate at a given time that has relevance to their needs.

All such programs in NSW would benefit by evaluations and for outcome data to be in the public domain. At the time of writing, a NSW review of Clubhouses is underway.

Policy Advocacy and Consumer Networks



TARGET POPULATION

- politicians, public administrators and public policy makers
- mental health and alcohol and other drug policy makers
- NSW and national policy spheres

RATIONALE

These models of assistance are most often **'indirect' capacity building mechanisms** rather than 'programs'. Policy advocacy networks usually take the form of incorporated membership associations of people with specific interests and expertise to contribute to public policy advocacy. They input to **whole of government and private industry policy** arguing that policy should promote protective factors for mental health, prevent risk factors and the onset of mental illness and suicide and which provide or support services for people at risk of mental disorders and problems.

Not all NGOs assume a policy advocacy role. Of those that do so, they may address issues **NSW-wide, local or regional** issues. Some are federated associations with like bodies in other states and with a watching brief on National and State health policy.

Not all policy advocacy is performed by **consumer-only groups** . Some associations are inclusive of all interests, being consumers, carers, professionals, academics and people from all walks of life. They therefore can take the view of a plurality of interests shaping mental health advocacy. It is

important to include members of the community who are naï ve to treatment services and mental health systems, but who can inform policy how to reach out effectively to the wider community.

Peak bodies provide a community voice across this plurality by finding common ground between organisations and synthesising this to policy makers through active research and consultation.

BACKGROUND

Example NGOs that perform public policy advocacy include AfterCare, Mental Health Coordinating Council, NSW Consumer Advisory Group, Community Consultative Committees, Mental Health Association of NSW, Association for the Relatives and Friends of the Mentally Ill, Schizophrenia Fellowship, major Churches who especially advocate for the amelioration of poverty and homelessness, Northern Beaches Mental Health Support Group, Hornsby Ku-Ring-Gai Association, Action For Mental Health Service Improvement Inc and many others.

The first secular public policy mental health NGO was the Mental Health Association, which commenced in 1928 as an association of academic psychiatrists, administrators and the public under the name of the Mental Hygiene Association [74] although ideas about how best to prevent mental illness have radically changed since those days.

The first National Mental Health Strategy legitimised and assisted improving consumer involvement in mental health services. This involvement ranges from policy input, research, consultative committees and input to the delivery of programs. In NSW a Mental Health Coordinating Council community development program successfully established, and has sustained, a network of 36 Community Consultative Committees to help implement this vision.

The first policy advocate NGO in mental health established in 1928. [74]

By 2006 NSW mental health services could call upon 36 Community Consultative Committees and 9 Consumer Networks to shape mental health service delivery. [9]

MODELS

- Consumer Consultative Committees established with health administrations
- Consumer Networks and consumer-only organisations
- Broad, inclusive membership associations
- Peak organisations representing sectors of NGOs
- Peak organisations representing fields of practice (NGO and other organisations)

PREFERRED PRACTICE MODELS

There are no 'preferred' models in the same sense that we evaluate mental health programs of other kinds. However governments have produced discussion papers outlining how they envisage policy advocacy to be helpful to policy making. There are many papers on frameworks for community consultation, for involving consumers effectively in policy processes and for models of peak bodies across all government departments. Research Centres exist that devote themselves to such questions.

It is generally agreed that governments, in seeking to meet needs equitably across society, require the voice of all groups across society as well as the voice of those directly affected by the quality of services as service consumers. Consultation at a range of levels is therefore needed. While NGOs claim to be 'representative' they can only represent the most interested individuals in a society in an issue, often the views of experts, or those closely involved personally with an issue, and wider perspectives must additionally inform health decision-making. Community Consultative Committees, NSW Consumer Advisory Group and Peaks initiate consultations or are funded to perform consultations and these can also mobilise more public engagement and health literacy.

Policy must also be informed at different geographic levels.

At a local level, the question is less about broad policy and more about service

quality, planning and operational delivery and priorities. By the mid 1990s Mental Health administrations in NSW established their own consumer consultants and community consultative committees (CCCs) to work in collaborative partnerships with Mental Health Services at local levels. These are not always voluntary, some having sitting fees for participants. They depart to varying degrees from the model of entirely voluntary-managed community organisations but their focus is to assist the quality improvement of mental health services in all sectors. The NSW Consumer Advisory Group and MHCC provide support to this mechanism.

At a State-wide level in NSW, numerous NGOs specialising in mental health formed the Mental Health Coordinating Council (MHCC) in 1985. They required coordination of NGO mental health advocacy, which is time and expertise intensive. As such, MHCC is a 'ground-up' representative body for NGOs active in mental health both as a primary or secondary focus.

From this mechanism a host of research, evaluation and development, quality improvement and capacity development initiatives have been developed. Without this, NGO mental health services would remain more fragmented and more difficult to access and wider public policy would be less sensitive to mental health issues from the community perspectives. MHCC brings sectors together.

Conclusion and directions

This 'evidence so far' overview of models of assistance provided by community organisations active in mental health in NSW is itself a summary. It therefore does not lend itself to further summarisation or an Executive Summary without serious threat to the accuracy of the evidence status reported for the potential outcomes in each model of assistance. Each evidence statement is specific to that evidence available for some outcomes, not others, since more evaluative research is needed. Moreover, our focus was principally, the outcomes for people with schizophrenia and psychotic disorders as a manageable start to ongoing evidence reviews. Accordingly, this review cannot be taken to apply necessarily to all consumers and people with mental health need served by NGOs.

As well, *Working on Strengths* has not covered all of the important work NSW NGOs perform. For example, we have not expanded upon the many counselling services provided, among them, screening and counselling for depression and anxiety, gambling and addictions counselling, sexual assault and complex trauma counselling and counselling related to the psychosocial adapting to and surviving mental illness. The evidence base for counselling approaches is complex and is well documented in numerous systematic reviews and clinical practice guidelines specific to different mental health problems. An evidence-audit of NGO-delivered approaches would require a separate undertaking.

Thus, we have only skimmed the surface. But we have achieved our aim to present an overview of the program logic within major categories of mental health NGO programs. The principal evidence justifications for these approaches have been introduced. The extent to which individual NGO programs are 'evidence-informed' and the extent to which their practices are consistent with best available evidence-based practice rests with organisations to determine

NGOs might consider:

Which outcomes do we achieve?

How do we know?

Do we effectively apply the use of outcome tools to test our effectiveness?

themselves through internal and independent program evaluations.

Thus, this 'work in progress' may only be expanded to include more precision and clarity once community organisations further elaborate their program models and in the public domain through published program evaluations. New generation NGOs will need to resource program evaluation and dissemination.

Most local models of assistance by NGOs fell into the categories 'a' to 'ci' in our program evaluation categories (in page 8 of the Introduction). Category 'a' was, 'emerging program model, not yet described in peer reviewed published literature, and not yet evaluated', 'b' was 'the model has been described, even replicated, but effectiveness is unknown' and 'ci' was 'model is evaluated overseas as effective for defined population when delivered by clinicians'. The case management literature is plentiful in category 'ci' with limited but emerging data available for case management models performed by other workforces and consumers. There is an emerging international literature on peer-led programs. This was not scoped here since at the time of writing the Victorian Government Mental Health Branch is commissioning a literature review on peer-led and consumer-led mental health community organisation initiatives and the evidence for their effectiveness and another review in the form of a discussion paper is available. [96]

Other than help line evaluations in relation to suicide prevention which included some NSW services, we found no level 'e' evaluations: 'e' was 'model is refined and evaluated as effective and cost effective for dissemination in NSW by NGOs. Some models of self-help groups, TOPs Self Treatment, and open employment and clubhouses are informed by category, 'd I' evaluations: ie 'Evaluated effective for defined population when delivered by NGO overseas'. These evaluations provide robust enough data for assisting NGOs redesign their programs toward the achievement of optimal outcomes, with the rider that consumers find such outcomes relevant to the recovery and that the new program replicates and re-tests components of effectiveness in the original program.

And ....

Are we opportunistic enough in achieving further outcomes relevant to and agreed by consumers?

Are programs structured enough to achieve outcomes and test the actual outcomes achieved?

The paucity of available published evaluations about and from NGO programs in Australia and in NSW requires immediate action. We do not propose NGOs be avalanched with surveys from outside investigators nor more government quality frameworks. Nor do we propose that NGOs become less 'hands on' and focus on 'research' rather than 'practice'. However more integration between the two and more valuing of evaluation is required. NGOs must have mechanisms for sufficiently robust evaluations around priority questions for them to remain responsive and relevant in an advanced knowledge-based economy.

The audit did establish that there is sufficient international research to justify many current approaches used in NSW. It also established the longevity of NGOs in NSW. But an outcome-oriented (evidence-developing and evidence-informed) NGO sector requires more evaluation of models used in local practice, without which, acceptability to consumers cannot be assumed as ongoing.

Existing knowledge from robust evaluations, if used, can assist further program development and refinement by NGOs. Service redesign in employment programs is implied in the direction of stronger partnerships with clinicians or clinicians being co-located within NGOs to strengthen psychological and psychosocial structure to some program components. Self-help programs, Clubhouses and Centre-based programs, might offer more structure to address more outcome domains — how they help families might be reviewed. Program enrichment, rather than necessarily radical redesign could enhance some programs, without loss to the social and strengths approach taken by NGOs which is valued by consumers. Such modifications should be informed by consumer mental health outcome monitoring done strategically in program evaluations, or routinely (see *Mapping the Difference We Make*, 2006) where this can be resourced and where it is feasible. None of the evidence replaces the need to retain highly individualised and personalised helping.

The review has also shown the importance of health care integration research and evaluation about the relative contributions of different systems of care. It shows in a number of cases, that it is two service systems and skills sets

And ….ultimately,

Are we evidence - informed organisations whose programs reflect fidelity the best available evidence for effectiveness?

working along side one another or working jointly for a time, that achieves more outcomes for individual consumers. It is not always the case that sequential care (from hospital to community setting) does the trick. Stronger, more intensive helping by two agencies rather than just the NGO or just the clinical service assuring a continuity of assistance follows consumers between settings of health care, is repeatedly emphasised in the literature. This is necessary for persons suffering complex and co-morbid conditions. **There is further opportunity to enrich the existing synergies between human service systems** to optimise individual and population mental health outcomes. This is a key responsibility of non-government organisations since this ensures access to NGOs by consumers with most disadvantage and disability. It implies not just 'filling service gaps' by NGOs that are inevitably left by government service provision but community-wide cooperation in the design and resourcing of programs.

Finally there continues to be major social justice outcomes that as a society, we have not fully addressed: the impoverishment attending persons with mental illness, their inclusion and full economic participation remains a challenge and a key contribution to this challenge is made by community organisations.

Service re-design, not quality improvement (of outdated models) is sometimes needed.

Partnerships might ensure skills are shared between settings for the most-in-need consumers, while maintaining NGO milieu and equal valuing of NGO contributions.

Appendix 1

NHMRC levels of evidence

Level	Definition
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 pseudo-randomised 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 parallel 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 pretest/post-test
V*	Minimal evidence such as testimonials

Source: National Health and Medical Research Council. *How to use the evidence: assessment and application of scientific evidence.* Canberra: 2000.

Appendix 2

Non-government mental health organisations within NSW and member organisations of MHCC

Action Foundation
Active Employment
Anglicare
Australian Foundation for Disability (AFFORD)
Aftercare Association
AIDS Council of New South Wales Inc
Alcohol & Drug Foundation of NSW
Cyrenian House
Alice's Cottages Incorporated
Alliance to Improve Mental Health Services - AIMHS
Anxiety Disorders Alliance
Association Of Relatives And Friends Of The Mentally Ill (ARAFMI)

- ARAFMI Central Coast
- ARAFMI Cronulla - Sutherland
- ARAFMI Illawarra
- ARAFMI Newcastle
- ARAFMI Wingecarribee
- Auburn Cottage, Inc

Banks House Support Group
Bankstown Women's Health Centre
Baptist Community Services
Bay Ami Accommodation Incorporated
Billabong Clubhouse
Black Dog Institute (University Research Institute)
Blackheath Area Neighbourhood Centre
Blue Mountains Food Service Inc (Lunch Club Project)
B.Miles Women's Housing Scheme
Counselling and Retraining for Employment (CARE)
Carers NSW
Castle Personnel Services Inc
Centacare - Psychiatric Rehabilitation Service (PRS)
Centacare Ageing & Disability Services
Charmian Clift Cottages
City Womens Hostel
Clarence Valley Community Program
Club Speranza (Suicide Prevention)
Coffs Harbour Employment Support Service Committee (CHESS)
Consumer Activity Network (Mental Health) Inc
Community Consultative Committees (CCC)

- Armidale CCC
- Bankstown Mental Health CCC
- Campbelltown CCC
- Central Sydney CCC
- Coffs Harbour CCC
- Inner City CCC
- Liverpool/Fairfield CCC
- Macleay CCC
- Manning CCC

- Mid Western Area Health Service CCC
- Mudgee CCC
- Northern Beaches CCC
- Northern Sydney Area Mental Health CCC
- Port Macquarie Base Hospital CCC
- St. George CCC
- South Eastern Consumer Network CCC
- Tamworth CCC
- Tenterfield CCC
- Tweed Valley CCC
- Wingecarribee CCC

Co.As.It (Italian Association Of Assistance)
Compeer
Compeer Illawarra
Counselling And Retraining For Employment - (CARE)
Creative Youth Initiatives
Disability Advocacy Network - DAN
Doña Maria Pre and Post Natal Support Network
Dympna House Incest Survivors Resource Centre
Exodus Foundation, Ashfield
Fair Go Health Forum
Family Drug Support
GROW
Grow North Coast Community Centre
Hope Unlimited Group
Hornsby Ku-Ring-Gai Association Action For Mental Health Inc
Hornsby Ku-ring-gai Lifeline & Community Aid Inc
The Housing Connection (NSW) Inc
Hunter Joblink Inc
Independent Community Living Association (ICLA)
Interchange Respite Care (NSW) Inc
JewishCare
Kaiyu Enterprises, Inc

- Lifeline
- Lifeline, South Coast
- Lifeline, Newcastle & Hunter
- Lifeline Western Sydney

Macarthur Disability Services
Mental Health Accommodation & Rehabilitation Services (MHARS)
Mental Health Association NSW Inc (including Depression and Mood Disorder Association and Mental Health Telephone Information and Referral Service and National Mental Health Week in NSW)
Mental Health Reconnect
Mental Illness Education Australia (NSW) Incorporated (MIEA)
Mid North Coast Living Skills / Rehabilitation Forum
Mid Western CAG Inc
Mind Matters Media Inc
Moomba Accommodation Services
Mountains Community Resource Network
The Multicultural Disability Association (MDAA)
National Association for Loss and Grief (NSW) Inc
Neami Inc
New Horizons Enterprises Limited
Newtown Neighbourhood Centre, Boarding House Project
Northern Beaches Mental Health Support Group
NSW Consumer Advisory Group For Mental Health (NSWCAG)
NSW Disability Discrimination Legal Centre Inc
NSW Rape Crisis Centre
NSW Users & Aids Association
Open Employment
On Track Community Services Inc (formerly Tweed Valley Mental Illness Fellowship)
Parramatta Mission
Peer Support Foundation of NSW
Personnel Employment Albury Wodonga Inc
Physical Disability Council of NSW
Progressive Employment Personnel (PEP)
Psychiatric Rehabilitation Association (PRA)

Richmond Fellowship Of NSW
Richmond Fellowship NSW, Hunter
Schizophrenia Fellowship of New South Wales
Support and Education for Living and Health (SELAH)
SOMA Health Association Of Australia Limited
Southern Community Welfare Inc.
Stepping Out Housing Program
Suicide Prevention Australia Inc (SPA)
Sydney Counselling Service (STEPS)
Sydney Women's Counselling Centre
The Salvation Army
The Station Limited
Triple Care Farm - Mission Australia
Uniting Care Nareen Gardens
Uniting Care - Supported Living
Wesley Mission Homeless Person's Services
Western Riverina Community Care
Westworks Incorporated (Penrith)
Wollondilly Camden Family Support Service Inc
Women And Mental Health (WAMH)
Women Incest Survivors Network
Woodville Community Services Inc

Public Mental Health Services and Mental Health Research Institutes without NGO status but with organisational membership to MHCC at 2006:

Hunter New England Area Health Service
Illawarra Mental Health Service
North Sydney Central Coast Area Mental Health Services
Northern Sydney Area Mental Health (AMH) Consumer Network
St. Vincent's Mental Health Service
NSW Transcultural Mental Health Centre
Black Dog Institute, The University of New South Wales (research institute)

References

1. Penrose-Wall J (2006). *Evidence Audit of Retrieved International Literature: Recovery and Psychosocial Rehabilitation Literatures*. Mental Health Coordinating Council of NSW. April 2006.

2. Mental Health Commission of New Zealand. *New Directions: International Overview of Best Practices in Recovery and Rehabilitation Services for People with Serious Mental Illness — Discussion Paper.*

3. Leff J. (2001). Why is care in the community perceived as a failure? *British Journal of Psychiatry*; 179:381-383.

4. Saraceno B (1997). Psychosocial rehabilitation as a public health strategy. Psychiatric Rehabilitation Journal; 20(4): 10-15.

5. Lauriello J, Lenroot AR, Bustillo JR (2003). Maximising the synergy between pharmacotherapy and psychosocial therapies for schizophrenia. *Psychiatric Clinics of North America*; 26: 191-211.

6. (McGorry et al) Royal Australian and New Zealand College of Psychiatrists (2005). Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of schizophrenia and related disorders. *Australian and New Zealand Journal of Psychiatry*; 39 (1-2).

7. NSW Health (2002). *Framework for Housing and Accommodation Support for People with Mental Health Problems and Disorders*. Sydney.

8. NSW Government (2005). *New South Wales Interagency Action Plan for Better Mental Health.* Sydney.

9. Bateman J & Johnston S (2000) *The MAPS Project.* Mental Health Coordinating Council and NSW Health Centre for Mental Health. Sydney.

10. Mental Health Coordinating Council (2006). *Member Organisation Directory.* Sydney.

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

12. Society for Prevention Research (2004). *Standards of Evidence Criteria for Efficacy, Effectiveness and Dissemination*. National Institutes of Health and Robert Wood Johnson Foundation.

13. Barton R (1999). Psychosocial rehabilitation services in community support systems: a review of outcomes and policy recommendations. *Psychiatric Services*; 50(4):525-534.

14. Bustillo JR, Lauriello J, Horan WP, Keith SJ (2005).The Psychosocial Treatment of Schizophrenia: An Update. *American Journal of Psychiatry*; 158: 163-175.

15. Cnaan RA, Blankertz L & Saunders M. (1992). Perceptions of consumers, practitioners and experts regarding psychosocial rehabilitation principles. Psychosocial Rehabilitation *Journal*; 16(1):95-119.

16. Nuttbrock MH, Rivera JJ, Ng-Mak DS & Link BG (1998). Outcomes of homeless mentally ill chemical abusers in community residences and a Therapeutic Community. *Psychiatric Services*; 49:68-76.

17. Mueser KT, Bond GR, Drake RE, Resnick SG (1998). Models of community care for severe mental illness: a review of research on case management. *Schizophrenia Bulletin* 24(1): 37-74. Cochrane Database of Reviews of Effects (DARE) 2006 Issue 1.

18. Rapp CA (1998). *The strengths model: case management with people suffering from severe and persistent mental illness*. Oxford University Press, Oxford, New York.

19. Penn DL, Waldheter EJ, Perkins DO, Mueser KT, Lieberman JA (2005) .Psychosocial treatment for first episode psychosis: a research update. *American Journal Psychiatry*; 162 (12): 2220-32.

20. Zygumunt A, Olfson M, Boyer CA, Mechanic D. (2004). Interventions to improve medication adherence in schizophrenia. *American Journal of Psychiatry*; 161(3): 581-582.

21. Walling DP, March DT, Relapse prevention in serious mental illness Chapter p.49-60 in Frese FJ III (Ed) (2000). The role of organised psychology in treatment of the seriously mentally ill. *New directions in mental health services*. Jossey-Bass. San Francisco.

22. Rosen A, Teesson M (2001). Does case management work? The evidence and the abuse of evidence-based medicine. Australian and New Zealand Journal of Psychiatry; 35:731-746.

23. Shern D, Tsembers S, Anthony A, Lovell A et al (2000). Serving street-dwelling individuals with psychiatric disabilities: outcomes of a psychiatric rehabilitation clinical trials. *American Journal of Public Health* 90.

24. Rickwood D & Mitchell S (2005). *Pathways of Recovery: Report of the National Consultation on Preventing Further Episodes of Mental Illn*ess. Auseinet. National Mental Health Strategy. Canberra.

25. Barry KL, Zeber JE, Blow FC & Valenstein M (2003). Effect of strengths model versus assertive community treatment model on participant outcomes and utilization: two-year follow-up. *Psychiatric Rehabilitation Journal* ; 26(3): 268-277.

26. Marshall M, Gray A, Lockwood A, Green R (1997). Case management for severe mental disorders. The Cochrane Library.

27. Chilvers R, Macdonald GM, Hayes AA (2002). Supported housing for people with severe mental disorders (review). The Cochrane Database of Systematic Reviews 2002, Issue 4.

28. Soloman P & Drain J (1995). The efficacy of consumer case management team: two year outcomes of a randomized trial. *Journal of Mental Health Administration*; 22: 135-146.

29. Felton CJ, Stastny P, Shern DL, Blanch A, Donahue SA, Knight E & Brown C (1995). Consumers as peer specialists on intensive case management teams: impact on client outcomes. *Psychiatric Services*; 46: 10: 1037-1044.

30. Victorian Human Services (1999). Psychiatric Disability Support Services Minimum Data Set (MDS) Analysis July-December 1997. Aged Community and Mental Health Division. Melbourne.

31. Victorian Human Services (2003). Psychiatric Disability Support Services Minimum Data Set (MDS) Analysis 1998-2001. Aged Community and Mental Health Division. Melbourne.

32. Morris A, Muir K, Dadich A, Abello D & Bleasdale M (2005). *Housing and Accommodation Support Initiative Report 1 Summary*. Social Policy Research Centre The University of New South Wales. NSW Health and NSW Department of Housing. August 2005.

33. Freeman A, Hunt G, Evenhuis E, Smith D & Malone J (2003). *High Support Accommodation for People with Psychiatric Disabilities — a survey of high support, very high suppor and residential rehabilitation services in NSW and assessment of the needs and satisfaction of consumers residing there.* Afercare Sydney.

34. Waghorn G & Lloyd C (2005). *The Employment of People with Mental Illness. A discussion document prepared for the Mental Illness Fellowship of Australia*. Policy and Economics Group Queensland Centre for Mental Health Research University of Queensland and Division of Occupational Therapy University of Queensland.

35. Lysaker PH, Bell MD & Bioty MS (1995). Cognitive deficits in schizophrenia. Prediction of symptom change for participation in work rehabilitation. *Journal of Nervous and Mental Disease*; 183 (5):332-336.

36. Bond GR, Dietzen LL, McGrew JH, Miller LD (1995). Accelerating entry into supported employment for persons with severe psychiatric disabilities. *Rehabilitation Psychiatry*; 40: 91-111.

37. Bond GR, Drake RE, Meuser KT, Becker DR. (1997). An update on supported employment for people with severe mental illness. *Psychiatric Services;* 48 (3):335-346.

38. Cook JA, Leff Hs, Blyler CR, Gold PB, Goldberg RW, Mueser KT et al (2005). Results of a multisite randomised trial of supported employment interventions for individuals with severe mental illness. *Archives of General Psychiatry*; 62 (5):505-512.

39. Cook JA, Lehman AF, Drake R, McFarlane WR, Gold PB, Leff HS, Blyer C, Roprac MG et al (2005). Integration of psychiatric and vocational services: multisite randomised controlled trial of supported employment. *American Journal Psychiatry;* 162:1948-1956.

40. Drake RE, McHugo GJ, Becker DR, Anthony WA, Clark RE (1996). New Hamshire study of supported employment for people with severe mental illness. *Journal of Consulting Clinical Psychologist*; 64: 391-399.

41. Drake RE, McHugo GJ, Bebout RR, Becker DR, Harris M, Bond GR, Quimby E. (1999). A Randomised clinical trial of supported employment for inner city patients with severe mental disorders. *Archives of General Psychiatry.*

42. Bell M, Lysaker P, Bryson G. (2003). A behavioural intervention to improve work performance in schizophrenia: Work behaviour inventory feedback. *Journal Vocational Rehabilitation*; 18(1):43-50.

43. Moll S (2003). Supported employment: evi dence for a best practice model in psychosocial rehabilitation. *Canadian Journal of Occupational Therapy*; 70(5) :298-310.

44. Lehman AF (1995). Vocational rehabilitation in schizophrenia. Schizophrenia Bulletin 21(4): 645-656.

45. McKay, C., Johnsen, M, Banks, S. & Stein, R. Employment transitions for Clubhouse members. *WORK*, 26, 67-74.

46. Vauth R, Barth A, Stieglitz RD (2001). Evaluation of a cognitive strategy training in vocational rehabilitation of schizophrenic outpatients. *Zeitschrift fur Klinische Pscholoigie und Psychotherapie*; 30(4): 251-258.

47. Vauth R, Corrigan PW, Clauss M, Dietl M et al (2005). Cognitive strategies versus self management skills as adjunct to vocational rehabilitation. *Schizophrenia Bulletin*; 31 (1): 55-66.

48. Shankar, J. & Collyer, F. (2002). Support needs of people with mental illness in vocational rehabilitation programs — the role of the social network. *International Journal of Psychosocial Rehabilitation;* 7:15-28.

49. Harding C (2000). Changes in Schizophrenia across time: paradoxes, patterns and predictors in Cohen (ed) *Schizophrenia into later life: Treatment, research and policy.* American Psychiatric Publishing, Arlington VA.

50. Marshall M, Crowther R, Almaraz-Serrano A, Creed F, Sledge W, et al (2001). Systematic reviews of the effectiveness of day care for people with severe mental disorders: 1) acute day hospital vs admission, 2) vocational rehabilitation; 3) day hospital versus outpatient care. *Health Technology Assess*; 5(21):1-75.

51. Macias C (2001). Massachusetts Employment Intervention Demonstration Project "An experimental Comparison of PACT and Clubhouse". Final Report.

52. Mowbray CT, Collins ME, Bellamy CD, Megivern DA, Bybee D, Zilvagyi S. (2005). *Social Work*; 50 (1):7-20.

53. Ansiewicz R, Mears J & Bolzan N (2001). *Support groups for people who have mental health problems: A needs assessment in New South Wales. A report to the NSW Association for Mental Health Inc.* School of Applied Social and Human Sciences, University of Western Sydney. February2001.

54. Kennedy M (1990). Psychiatric hospitalisation of GROWers. Paper presented at the Second Biennial Conference on Community Research and Action. East Lansing Michigan.

55, Young, J (1991). A research evaluation of GROW, a mutual help mental health organisation. University of Tasmania. Doctoral Thesis.

56. Kurtz LF (1988). Mutual aid for affective disorders. The Manic Depressive and Depressive Association. American *Journal of Orthopsychiatry*; 58 (1): 152-155.

57. Raiff NR (1984). "Some health related outcomes of self help participation". Chapter 14 in *The Self Help Revolution*. Gartner A & Riessman F (eds), New York. Human Sciences Press.

58. Chien WT & Chan SW (2004). One year follow-up of a multiple-family group intervention for Chinese families of patients with schizophrenia. *Psychiatric Services* ; 55 (11): 1276-1284.

59. Schubert MA & Borkman TJ (1991). An organizational typology for self-help groups. *American Journal of Community Psychology*; 19(5):769-787.

60. Citron M, Solomon P & Draine J (1999). Self-help groups for families of persons with mental illness: perceived benefits of helpfulness. *Community Mental Health Journal* ; 35(1)15-30.

61. Schulze Monking H (1994). Self help groups for families of schizophrenic patients: formation, development and therapeutic impact. *Social Psychiatry and Psychiatric Epidemiology* ; 29(3): 149-154.

62. Magura S, Laudet AB, Mahmood D, Rosenblum A, Knight E (2002). Adherence to medication regimens and participation in dual-focus self-help groups. *Psychiatric Services* ; 53(3):310-316.

63. Krch F (1991). Organisation of self-help groups for patients with psychogenic eating disorders. *Ceskoslovenska Psychiatrie*; 82(2): 86-91.

64. Paton G & Burns J (2000) Preventive Interventions in Youth Suicide: A risk factor based approach in *Setting the evidence based research agenda for Australia a Literature Review*. National Youth Suicide Prevention Strategy. National Youth Suicide Prevention Strategy. Canberra.

65. Pfeffer CFR, Jiang H, Kakuma T, Hwang J & Metsch M. (2002). Group intervention for children bereaved by the suicide of a relative. *Journal of American Academy of Child and Adolescent Psychiatry*; 41 (5): 505-513.

66. Balke K (1995). Status of health policy and possible support to self help groups. *Gesundheitswesen*; 57 (11):706-709.

67. Mitchell P (2000). *Valuing Young Lives Evaluation of the National Youth Suicide Prevention Initiative* (report series) Australian Institute of Family Studies.

68. Dew MA, Bromet ET, Brent D, Greenhouse JB (1987). A quantitative literature review of the effectiveness of suicide prevention centres. *Journal of Consultant Clinical Psychology*; 55:239.

69. Perkins D, Fanaian M (2004). *Who Calls Lifeline : Baseline study of callers and their needs Final Report*. CEPHRIS Centre for Equity and Primary Health Research in the Illawarra and Shoalhaven. University of New South Wales.

70. Lifeline Australia Inc. (2003). *Lifeline in Mental Health A Perspective on the Mental Health Needs of the Australian Community 2002.*

71. Urbis Keys Young (2003). National review of tele counseling and web counseling services final report. Department of Health and Ageing. Canberra. www.mentalhealth.gov.au/resources/reports/counsel.htm

72. Christensen H, Hocking BM, Smith D (2004). Web and telecounselling in Australia. (Editorial) *Medical Journal of Australia*; 180(12): 604-605.

73. Mental Health Matters *Magazine of the NSW Association for Mental Health (4) 1995.*

74. Mental Hygiene Association Inaugural Meeting. (1932). Minutes Reported in the *Medical Journal of Australia* 1932.

75. "What is a Clubhouse" Schizophrenia Fellowship of NSW Website.

76. Adamson L, Mullavey-O'Byrne C & Clubhouse Member Informants (undated). *Clubhouse Research: Members' reflections: experience and meanings.* Website of the Schizophrenia Fellowship of NSW Inc.

77. Kivelitz H (2002). *Clubhouse – a Leader in the Field.* Paper on Sydney's Pioneer Clubhouse. 5th Australasian Clubhouse Conference, Brisbane.

78. Bae S, Brekke JS & Bola JR (2004). Ethnicity and treatment outcome variation in schizophrenia: a longitudinal study of community-based psychosocial rehabilitation interventions. *Journal of Nervous and Mental Disease*; 192(9): 623-628.

79. Baker F, Stokes-Thompson J, Davis O, Hishinuma E (1999). Two-year outcomes of psychosocial rehabilitation of black patients with chronic mental illness. *Psychiatric Services;* 50:535-539.

80. Delaney C. (1998). Reducing recidivism: medication versus psychosocial rehabilitation. *Journal of Psychosocial Nursing and Mental Health Services;* 36(11): 28-34.

81. Robertson L, Connaughton J, Nicol M. (1998). Life skills programmes for chronic mental illnesses (Review). *The Cochrane Database of Systematic Reviews 1998 Issue 3.*

82. Mowbray CT, Collins ME, Bellamy CD, Megivern DA, Bybee D, Szilvagyi S (2005). Supported education for adults with psychiatric disabilities: an innovation for social work and psychosocial rehabilitation practice. *Social Work*; 50(1): 7-20.

83. Colom F et al. (2004). Psychoeducation in bipolar patients with comorbid personality disorder. *Bipolar Disorder*; 6(4):294-8.

84. Owens DGC, Carroll A, Fatt S et al (2001). A randomised controlled trial of a brief intervention package for schizophrenia outpatients. *Acta Psychiatrica Scandinavica*; 103:362-369.

85. Pekkala E, Merinder L (2002). Psychoeducation for schizophrenia Review. *The Cochrane Database of Systematic Reviews 2002 Issue 2.*

86. Dodds F, Rebair-Brown A, Parsons S. (2000). A systematic review of randomised controlled trials that attempt to identify interventions that improve patient compliance with prescribed antipsychotic medications. *Clinical Effectiveness in Nursing*; 4: 47-53.

87. Steicker SK, Amdur M, Dincin J. (1986). Educating patients about psychiatric medications: failure to enhance compliance. *Psychosocial Rehabilitation Journal*; 9:15-28.

88. Glynn SM, Marder SR, Liberman RP, Blair K, Wirshing WC, Wirshing DA, Ross D & Mintz J (2002). Supplementing clinic-based skills training with manual-based community support sessions: effects on social adjustment of patients with schizophrenia. *The American Journal of Psychiatry;* 159(5): 829-837.

89. Ruddy R, Milnes D (2005). Art therapy for schizophrenia or schizophrenia-like illnesses (Review). *The Cochrane Database of Systematic Reviews* 2005 Issue 4.

90. Chambless DL, Baker MJ Baucom DH, Beutler LE, Calhoun KS et al (1998). Update on Empirically Validated Therapies II. *The Clinical Psychologist*; 51(1): 316.

91. Bracke P (2002). Peer support and support from staff during psychosocial rehabilitation. *Mens en Maatschappij*; 77(1):43-64.

92. Yildiz M, Tural U, Kurdoglu S, Emin Onder M. (2003). An experience of a Clubhouse run by Families and Volunteers for Schizophrenia Rehabilitation. *Turk Psikiyatri Derg*. 14(4): 281-287.

93. Lucca AM (1998). *Relationships among program components, social environment, and member functioning in psychosocial rehabilitation programs for seriously mentally ill individuals*. University of Connecticut PhD Thesis.

94. Zalusa M, Suchecka D, Traczewska Z, Paszko J (2005). Implementation of social services for the chronically mentally ill in a Polish mental health district: consequences for service use and costs. *Journal of Mental Health Policy and Economics*; 8(1): 37-44.

95. Sobel D S (1995). Rethinking Medicine: Improving Health Outcomes With Cost-Effective Psychosocial Interventions. Psychosomatic Medicine; 57:234-244.

96. Conner H (2005). *Consumer Operated Services Discussion Paper*, March 2005. Australian Health Ministers' Advisory Council National Mental Health Working Group, Australia.

97. Muir K, Dadich A, Abello D et al (2006). Housing and Accommodation Support Initiative Evaluation Report III Summary. Social Policy Research Centre. UNSW. January 2007.

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