

Practical ways for consumers to get more out of mental health services: Changing maps and making different roads to recovery

by Allan Pinches and Sue Robertson

Mental health services are changing.

So it's important for consumers to be able to become more informed about new opportunities arising from a service system which is more dispersed across a range of community settings, and could pose complications as well as potential benefits.

Consumers can, with the right information and encouragement become more skilled at navigating the new system and using services more pro-actively, and can potentially gain from:

- **a wider range of choices of treatment and support methods.**
- **a growing flexibility and integration of services within the community.**
- **some early progress towards the ideal of consumers becoming true partners in their own treatment.**
- **services becoming increasingly willing and informed about working from a more holistic and recovery based range of approaches.**

This knowledge enhancement in consumers and service providers could have widespread effects and greatly assist consumers in their journeys of recovery.

The "Old System" with its horrific asylum-like institutions has finally virtually crumbled away, with the advent of deinstitutionalisation and mainstreaming of services, and many mental health services have now shifted into the community. While the system is still far from perfect, and is often severely over-stretched - with significant numbers of consumers missing out on getting a full range of services, particularly in the clinical area - there have been significant improvements overall.

Case Management at Community Mental Health Centres, with increased linkages to other services in the community, is now the preferred service model for coordinated clinical care and treatment of clients, and this offers at least the beginnings of new choices for consumers and a

range of more flexible and holistic approaches.

Crucial further work needs to go into progressing consumer participation activities and programs, with the aim of helping plan and develop mental health services which better fit the shape of consumers' needs and reflect their lived experiences.

Consumer participation, when supported and resourced in ways that allow it to achieve more of its potential, and when carried out in developmental and collaborative ways with key stakeholders, can be a major resource for service improvement – and it is gaining a solid track record of achievement.

However, it also seems likely that further enhanced and developed consumer participation in many different forms, could provide an effective and unique information source within service delivery -- through consumer participation at the level of individual service users and collective consumer advocacy – with great capacity for “unlocking” much extra potential within actual service delivery.

Challenges within the Service System

There are very significant challenges involved in trying to assist consumers in navigating a complex maze of services, and to improve the availability and coordination of a more dispersed mental health service system which often don't seem to be sufficiently “joined up” or have the various parts talking to each other very effectively – or there might also be crucial sections missing in some localities.

Some areas of the mental health service system where consumers consistently identify problems of short supply and severely over-stretched services are: supported housing, public housing, services to homeless people with mental illness, psychiatric ward acute care beds, adequate crisis response services including appropriately “sensitised” hospital emergency departments, personal counseling, carer and consumer respite services, services catering to people from Indigenous communities and culturally diverse groups, supports for consumers to access “mainstream” employment options, supports for education participation, and many more areas.

In the community sector of mental health there are psychiatric disability rehabilitation and support services (PDRSs) in Victoria, such as Neami Ltd, or the Richmond Fellowship of Victoria, or the Mental Illness Fellowship of Victoria, which are responsible for providing consumers with disability support, housing, rehabilitation, social, recreational, vocational/ employment programs, and assistance in making connections to community services and educational services.

These community-managed services have stated aims of assisting people with psychiatric disability to live successfully in the community, within a fulfilling, self-determined quality of life, based on the person's own individual needs and values. While a worker and client may work together to generate whole lists of options, and may explore many diverse strategies and goals, consumer advocates tend to say that ideally it is best for people to be supported and resourced in ways appropriate for achieving their own self-determined goals.

Such services often have mission statements that espouse such values, and place a strong emphasis on concepts like empowerment, recovery, achieving human potential, skills development towards independent living, consumer participation in decisions affecting them, and community development based approaches, and many other things.

Some of the main service models offered by PDRS services include key support work, outreach support which supports consumers in their homes and local community settings, special purpose group work, “drop-in” (a service element often more valued by consumers than service providers) outings, and assistance to make community linkages, consumer participation opportunities, and more.

Building in a Recovery Focus

Recovery from mental illness is a concept which has gained huge momentum from the consumer movement in the past decade, mainly from America in the work of consumer activist-psychologists such as Dr Patricia Deegan and Dr Cheryl Gagney.

Consumers and their supporters are advocating for and in many ways attempting to pursue more holistic and humane alternatives to the medical model of mental illness, which tends to reductionism and self-fulfilling prophecies of “chronic” this “treatment resistant” this or that diagnosis. Institutionalisation and over-medication have been implicated for much of the disability seen in people, and as PDRS services and other supports come into place, many consumers are doing much better in the community and taking self-initiated steps toward recovery and reclaiming control of their lives and destinies.

A study by Dr Barbara Tooth and some colleagues in Queensland asked consumers who considered themselves to be “in recovery” about factors which had helped and hindered them on their recovery journeys.

Mental health professionals were not rated as particularly helpful, and sometimes actually harmful to recovery – except for those who showed extraordinary humanity and caring, and were prepared to “go the extra mile” and show consumers something approaching genuine friendship. The message coming out this important qualitative research funded by a Federal Government grant, was that consumers are vindicated in saying: Just treat us as people, with care and compassion and we will get better.”

As one research and development project in the field, Neami Ltd has done extensive work on blending the concept of recovery with psychosocial rehabilitation, and has generated a document, with considerable consumer input, which strives to bring the two together.

The working document from March 1999 says in part: “Recovery is a consumer-centred experience based, importantly, on a developed sense of self as the basis of coping and mastery of critical areas of life. It incorporates the realisation of capacity to act in one’s own interests, of goal setting and testing out strengths through personal action.”

This would require many changes in service practices and cultures. The document continues: “We should be providing services that build a structure wherein consumers can safely explore

options, experiment with choice making and risk taking and develop skills and confidence. We should be building bridges within mainstream community groups, playing an advocacy role, in addressing issues of access and participation.”

Peer Support and Valuable Consumer Knowledge

In an initiative over the past few years there have been consumer-run peer support activities and outings among consumers in the Darebin Neami and the local Community Mental Health Centre, based on the idea of "Friends Supporting Friends." Many consumers have expressed a desire to better help and support their friends, but felt they needed more knowledge and skills. Some skills development and education to promote peer support networking and friendships are being considered.

There are also early proposals - strongly supported by some senior staff and managers to seek innovative funding for employment of peer support workers, perhaps to be shared between local clinical and Neami disability support services. A similar model is used in some services in the US, where appropriately trained consumers work as assistant case managers, and if it goes ahead this would be a major breakthrough on the Australian scene.

Now more than ever - with growing co-operation and partnerships between clinical and disability support services and new service models, such as GP shared care, and moves towards peer support - there are many opportunities for consumers to use mental health services in more diverse and pro-active ways. But this opens up a number of questions, for service providers and consumers to think about, as follows:

- How can consumers be supported and enabled to fully utilise new opportunities for more diverse and individually tailored approaches, offered by recent developments?
- How can consumers best be informed about and have a say in what choices of treatment, support and rehabilitation methods are available or what alternative methods or community facility linkages might be possible?
- How can consumers be assisted in assessing the benefits and deficits and degrees of relevance of options on offer?
- Is there enough scope for disagreement and enough information for consumers to make decisions based on informed consent?
- How can the person be aware and able to control whether treatment and rehabilitation methods being used reflect their own values and goals or are they more about acquiescence to what is increasingly seen as the prevailing “hard culture” of the present social and political times?
- How can consumers be expected to re-integrate into a "community" that arguably does not exist - in the true sense of the word, with strong connotations of mutual caring, sharing and inclusiveness?

Ideally service providers and consumers can meet half-way - with a fairly steep learning curve

on both sides, requiring much collaborative dialogue.

Clinical service providers collectively need to learn how to surrender some processes of power and control, and move away from coercion and compliance based thinking more toward a model of participatory discussion with consumers and their advocates. (The community sector tends to be stronger on this, but admittedly has the advantage of not having to deal with "involuntary" consumers.)

In fact, many clinical service providers are now trying hard to provide more partnership-based treatment for people, characterised by more flexibility, wider choices, tailored to individual needs, better integration of clinical and disability support services, more information, better linkages to other community facilities and increased consumer participation in planning, development and delivery of services.

One senior clinical manager suggests a "modular" service system, where a consumer could be "walked through" a brochure featuring a wide range of service options -- or "modules" -- which could be "mixed and matched" according to a consumer's needs and wants - similar to the format of a health insurance application brochure. Different mixes of services could be offered, including varying roles and methods for case managers, disability support workers, GPs etc, and offering many different ways of working, such as peer support and learning-based groups, peer support workers, or cluster case management, say for several people with similar issues.

Consumer Participation and Empowerment

At the same time many consumers would benefit from collective action and exploring ways to exercise their new potential power, which has been hard won by years of advocacy efforts and debate. As well as collective action by consumers and consultation, there is a clear need for an educative process to take place.

Empowerment means not only a service system handing back more power and resources to service users, but also providing opportunities for consumers to become more *educated about the new service system works and be more informed about some ways they can more beneficially exercise some of the new choices or approaches.* There is a need for a "listening" part of such processes too, so that the experiences and needs of consumers can be built into service delivery at all levels.

There are indications that there is quite a steep learning curve ahead for many consumers - and service providers too -- because for decades we have been conditioned by a largely unenlightened system to be passive recipients of treatment, with few choices, and were often offered little hope or encouragement-- let alone "empowerment" style education.

Knowledge is the *active ingredient* of empowerment.

Many consumers need to become aware of their rights and responsibilities in the gradually emerging new-style system; they may be well advised to:

- learn to navigate the system, exploring all available resources including ways of linking in to facilities in the wider community;

- ask questions about methods and options to ensure that medication or other therapeutic and rehabilitation methods used really do suit them personally;
- take a pro-active approach to treatment and rehabilitation; being politely assertive about the choice of workers, methods or services, and,
- ensure the combined helpers work with him or her collaboratively and in a coordinated manner.

Service providers, consumer advocacy groups and peer support groups need to be active in helping consumers to organise, share ideas and to work through the necessary education and consultative processes.

From Experience...Some Possible Self-Help Strategies for Consumers

In this article, based on long experience as service users and consumer representatives, in disability support and clinical services, we will now offer some practical suggestions of how consumers can use their key worker relationships - whether it is with a clinical case manager or doctor or with a disability support worker - more pro-actively and to S-Q-U-E-E-Z-E the most possible healing and well-being "juices" out of the key worker relationship.

Some suggested approaches follow:

Ask lots of questions: maximise your options by asking your key worker to outline a full range of such methods and strategies as:

-treatment and/or rehabilitation methods available and how they interrelate.

-available services in the area.

-possible linkages to other community facilities.

-choices/ requests of optimal medication types and levels that suit the client individually, effects and side-effects, benefits and deficits, and scope for negotiation, remembering that over-prescription can be very disabling.

-self-monitoring, coping and self-management techniques which may have helped others, particularly consumer-generated ideas.

- Day to day support needs and the client's own personal support network.

-Crisis contact numbers and a rough guide to the worker's times of availability.

-special "contract" items between the worker and client - ie, what the key worker will or won't do and what the client will or won't do. Within certain limits governed by the worker's statutory duty of care, the client can negotiate about interventions or methods they find appropriate or not, and

in turn they can give guarantees about behaviour not acceptable from them.

"Brainstorm" with your key worker on what conditions you would like to manifest in your life and what you would like to achieve, say in the next two to three years. For instance, in terms of work/meaningful activity, education, creative outlets, recreation, social and support networks, personal relationships, sexuality, spiritual/wholeness needs, mental and physical health, accommodation, self-care, finances, possessions, travel, holidays and fun, plus any other important aspirations the client might have. Individual Service Plans can be a very helpful tool for this process. It helps to have clear objectives.

Start with small, realistic and achievable goals. As you fulfill your goals and grow in confidence, with each success, you can get progressively more ambitious. (But remember the ancient wisdom that it is often not the destination, but what is learnt and experienced on the journey that counts. It may be the many spin-offs of an activity that holds the value, rather than the activity itself. Venerated psychologist C.G. Jung was once asked what was the surest path to self-realisation. He replied without a second's hesitation: "The *detour*. Always the detour."

Develop a "toolkit" of self-help methods and strategies to help you get out of difficulties at any time. This can be simple or elaborate, and would consist of such things as self-healing, coping, monitoring, self-management, "grounding" and reality checking methods that you can individually swing into action when needed. These may range from affirmations on wall charts, a self-designed "program" of daily activities or helpful reading materials, through to stress-relieving meditation, using relaxing music or taking interest in study or a hobby. It is really important to not become too isolated, look after one's physical health, have good nutrition, get regular exercise and avoid harmful substances. All these issues could be strategically addressed by "toolkit" items.

Track your progress, new insights and "breakthroughs" by keeping a personal journal. As well as helping to keep you on track, and provide inspiration during hard patches, writing about issues and feelings can help with coming to terms with issues; dissipating associated anger over issues just like talking about it, and stopping worrying cycles with tangled issues "going around and around" in your head, by sort of "pinning" them on paper, releasing you from the need to keep them in your active memory, and allowing you to get on with other things. Some therapists even suggest a dedicated "worry time" for an hour each day, at a fixed time, deferring worrying to that time. It is also a good idea to try to do any "homework" your key worker may suggest. It can be helpful to take notes during sessions with the key worker. This is also an ideal opportunity to try "open charting," a system where the worker and client jointly write up case notes.

Allocate time for FUN, ENJOYMENT, and HUMOUR. Make sure you get time for walking outdoors, enjoying nature. Light and the colours of nature are therapeutic, and exercise can help lift depression because it triggers brain chemicals called endorphins, which affect the pleasure centres of our brain. And walking is great for getting fitter, slimmer and healthier. Try to schedule in at least one activity that you genuinely enjoy every day, as this can give you a big lift. And "Laugh and the World Laughs With You..." Watching selected sitcoms on TV can help

beat the "blues", or hiring a comedy video. There are also cheap-priced tryout nights for rookie comedians you can go to, which can be fun. Or being in a studio audience for TV comedy show tapings which are often free. If you sometimes find it hard to see the funny side of life situations, one key pointer may be taken from one Stand-up Philosopher's wry observation: "Comedy is the difference between humankind's potential, and what we *actually* do!"

Learn to appreciate the "little things" about life that are affirmative and good. A smile from a friend, an unexpected act of kindness from a stranger, a little baby, a beautiful scene in nature as you soak up the sunshine beneath a friendly old tree. That's how it begins. Soon more and more substantial positives will come to light, a bit like Pollyanna from the famous children's book of the same name, and her optimistic "Glad Game." (*The idea is like counting one's blessings, whereby the player makes up a list of as many things as they can think of to be thankful for... i.e., "I'm Glad that..."*) If you find yourself jaded about life and lacking hope and interest in things, it seems from the experience of some recoverers that there is just a hair's breadth of distance between being interested in *nothing* and being interested in *everything!* It just takes a small shift of mental outlook, often fortuitously helped along by a little Ray of HOPE.

Revised Version, February 2004.

First version 1998.

(Original version titled:

"Practical ways for consumers to get the most out of their key worker relationships."

***Allan Pinches** is a former metropolitan journalist who currently works as a Consumer Consultant for the Northern Area Mental Health Service in Melbourne. He is a former consumer member of the Neami Ltd and Richmond Fellowship of Victoria boards. He is a past Vice-President of Neami Ltd. Allan regularly writes articles for mental health publications in print and on the Internet and is a frequent conference speaker, educator and workshop facilitator. Allan has recently successfully completed his studies for a Bachelor of Arts (Community Development) at Victoria University of Technology. Allan has a **website** featuring consumer-perspective articles on various mental health issues at: <<http://www.alphalink.com.au/~alpin>>

***Sue Robertson**, BA, (Monash) is a pioneering Neami Ltd consumer, who served on the organisation's board as a consumer member for five years. Sue also actively participated in the life and development of Neami's Catch 23 Day Program in Thornbury. Sue has been extensively involved as a consumer panelist in staff selection processes for Neami. Sue is currently an active contributor to a number of consumer participation programs, including Northern Area Mental Health Service's Thinking CAP consumer group and the Northern Women's Mental Health Network.
