

Talking to clinical mental health rehabilitation staff about what the consumer movement says about “Recovery”



by Allan Pinches,
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Hi, my name is Allan Pinches and I am a Consumer Consultant for Mental Health -- a role which basically facilitates communication and a range of consumer participation activities in service planning and development. I get to go to a lot of meetings, write a lot of reports, and speak about consumer perspectives in many service and community settings.

I think this kind of service planning day provides valuable opportunities. It can draw together the knowledge that exists within the staff as a group; people can work as a team and focus on issues in the service; they can develop and share the best ideas and best practices; they can highlight the things that are working well and identify the problems; and then try to find solutions.

This is also very much about the reinforcing the things that are the positive -- and building on them, supporting them, systematising them and resourcing them -- so that the services can perform as well as possible.

Necessarily, much of the focus comes down on the ways the service can help to improve the mental health and the lives and expectations of the consumers.

So to be invited today to talk about the concept of recovery was really exciting for me, because I suppose for a clinical service to be including a talk about the “R” word in such a planning day is a real breakthrough in some ways and I am just so pleased to be a part of it.

I want to talk a little bit today about what the concept of recovery means to mental health consumers, from the perspective of the consumer movement, because recovery from mental illness is actually a concept that has been largely developed, articulated and driven by consumers, with growing support from service providers, over time. I will also try and link the notion of recovery back to what I believe are a number of implications for service delivery at a local level, particularly in relation to treatment practices and relationships, and service design and implementation. So that is a fair bit to cover in 20 minutes, but I will do my best.

The idea of recovery in a mental health context, it is something that has been building up for about the last 10 years as a major theme to be championed by the consumer movement -- a very big and growing movement in America, and the UK and parts of western Europe and Australia. The mental health consumer movement is closely related to disability rights movements and independent living movements and various other areas of social change and community development.

The underpinnings of concepts of recovery from a consumer perspective, is that what is called “mental illness” is not this big, exotic and amorphous thing – like an immovable block of wood -- as it often seems to be characterised in society and to some extent in services. Approaches based on notions of recovery tend to question some aspects of the so called “medical model” of psychiatry, or at least advocate for consumers to be offered a wider or more “holistic” range of treatment and rehabilitation approaches.

The recovery paradigm, as articulated by people from the consumer movement, says there are many ways of influencing these states that are called “mental illness” and that people can achieve at least some degree of recovery -- given the right conditions for personal empowerment, the right support, the right programs, the right relationships between consumers and service providers, the right peer support, the right community linkages, and many other psychosocial and social model of health based approaches.

When the consumer movement talks about recovery they are not necessarily talking about a complete ceasing of symptoms or an outright cure, in a medical model sense, but usually something more in the realm of better coping, improved quality of life, improved expectations, improved abilities to function the community, greater ability to be active in various ways, to have a peer group, to have relationships, to have some family context, and other things important to individuals.

The concept is something along the lines that it is quite possible for your “life to recover” although you may or may not still have some degree of symptoms or illness. In other words, the main domain of recovery may be in one’s life and situation, but many consumers do also report a reduction or even ceasing of symptoms, once some positive changes get underway.

Many consumers have expressed a preference for a description of being “in recovery” as distinct from being “recovered.” This implies an active, dynamic and ongoing process, which is qualitative, unfolds in variable and non-linear manner, and one defined within the subjective experience and life world of the consumer. It has much to do with the areas of personal empowerment, relationships, and quality of life.

I think it’s an important point that recovery is a very normalising concept, and that a lot of power and potential really resides within the idea of *recovery as an everyday process*, and a natural part of the human condition. Everyone in the world has to recover from something, and go through processes of recovery, at some time or another -- whether it is from the death of a loved one, or a broken relationship, or it might be from an illness, or

it might be from the loss of a career. It could be all sorts of things that people have to recover from in all sorts of ways.

As a society we often fail to recognise the human face of many issues we come to regard as social problems, often involving supposed “problem people” and we don’t tend to learn the necessary lessons arising from the lived experiences of people until long after we and our governments routinely spend millions of dollars trying to remediate problems that should have been somewhat predictable and preventable in the first place.

So there are ways of seeing the lives of people who experience what is called “mental illness” as not being this exotic or “other” thing.

As observed by critical social philosophers such as Michel Foucault, people with mental illness have historically tended to be characterised as “the other” along with a number of social groupings subject to classification and control. (See Foucault, Michel (1989) *Madness and Civilization: A history of insanity in the age of reason.* Tavistock/Rutledge, London and New York. First published in French as *“Histoire de la Folie”* in 1961 by Librarie Plon.)

Apart from issues to do with diagnosed mental illness or mental health and other relevant services, notions of madness are subject to heavy social stigma and widespread misunderstanding, and are negatively portrayed in the media, advertising, and popular culture. So we see headlines about “dangerous psychotics” and we all hear long lists of synonyms in colloquial language for notions of madness – you know, crazy, around the bend, loopy, off the planet, a shingle short, loose kangaroos in the top paddock, etc -- and TV advertising using stereotyped images of madness such as the red-hot salesman “Ken Bwooze has gone mad” complete with his straightjacket, or ads for “Crazy Joey’s” mobile phones, and all that sort of thing. Its almost like we need a furniture-electrical-bedding crisis recovery centre to be set up somewhere, with all this retail-inspired craziness going on!

So I suppose what we really need to do is get back to the realisation that people who have an experience of emotional distress or trauma, which later leads to mental illness and various other social factors that impact on people and can contribute to the incidence of mental ill health, can be regarded as something that is part of the continuum of human experience -- not some strange, alien and “other” thing that happens to those people over there.

That kind of thinking historically has contributed to a long succession of rather strange and rarified ways of treating people with “mental illness” -- which is probably why we had those big institutions for the “mentally ill” and other unfortunates from jolly old Dickensian England onward. I know that things have over time changed for the better, and that while deinstitutionalisation and mainstreaming of mental health services have been subject to many problems and under resourcing, they have been of benefit to many consumers and opened up many new options for people to live and participate in the community.

This has provided a grounding for even beginning to think about things like recovery. I also think the emergence and growth of psychiatric disability rehabilitation and support services (PDRSs) in the last 20 years has made a very significant difference and there are increasing linkages between clinical services and PDRSs and a whole range of community services.

Providing community linkages for consumers is really an important part of any recovery approach.

Just give some further background, in case you were interested in doing some further reading, there is so much that has been written about recovery from a consumer perspective.

Two notable leaders or pioneers of this approach are two particular psychologists from the USA who themselves have a consumer background. They are Dr Cheryl Gagne, PhD and Dr Patricia Deegan, PhD, and they actually have done a lot of writing and conceptualising about what the recovery is, how it can be promoted, different ways of looking at it, how it can fit into service delivery, and putting it in the broader social context.

I think Dr Gagne and Dr Deegan, who have apparently developed their work separately, have also remarked on the unhelpful effects of the self fulfilling prophecies implicit in the very pessimistic standard prognoses and presumptions of intractability of mental illness over much of the last 100 years of psychiatry -- so much that when you were admitted as a patient you soon got the notion "abandon all hope ye who enter here."

To access many writings and links for Dr Deegan on the Internet, you can go to the website of the National Empowerment Centre at: <http://www.power2u.org>
For many links and writings of Dr Cheryl Gagne you can access the website of the Centre for Psychiatric Rehabilitation, Boston University, at:
<http://www.bu.edu/cpr/about/profiles/cgagne.html>

A major area of difficulty for consumers was the practical and social deskilling they experienced in institutionally based services, plus taking away the hope and taking away the personal interaction and the respect and the humanity -- is it any wonder that people have been over time and back then so much, so grossly affected, so grossly limited, how they came looking for help and the in fact got further debilitated by a system which really wasn't adequately geared up to helping people in any real way. A large part of the problem has been the removal much of the real world context of people's lives.

It's really important in doing rehab work with consumers to help maintain this normalising real world focus because that was missing in the institutional days -- and there are still are the signs of it today here and there in services -- and this can create a sort of "hot housing" of people's illnesses, because people get the idea that they are so very ill, and if they are removed from all these contextual day to day realities and

responsibilities and expectations and occupations, then there is really very little room for their situation to grow apart from being trapped in an illness paradigm. This kind of hothouse reality can arise for the consumer because of the lack of grounding factors and real world context and normalising context and that there isn't a horizon line. Without those things it is very hard to orient yourself. You actually need that grounding, and I think that this is another important concept.

And there is a need for those who work with consumers to be very encouraging and hold out hope I think. Hope is the thing that works, if you take away anything today I think that this word "hope" is at the centre of rehabilitation and recovery.

But just to offer some hope to you as a group of professionals and clinicians who are very up against it trying to do a hard job and with very real constraints and difficulties every day -- and those things have to be acknowledged -- I would say that you can look at what your service has achieved and has been acknowledged for in its 6 year history. It is a story with great relevance to the concept of recovery, and in ways which exceeded expectations.

Clearly there must be a lot of things within the service that have involved really very good practices, very good relationships, very good structures and processes, to get such an outcome.

We can learn from the positive results of the work that has gone into building good relationships with consumers, of going that extra mile in working with consumers and their often somewhat disconnected families. The good achievements have been helped by efforts to create a more normalised context for people, with a more supportive environment, and more opportunities to gradually try new things. It has also been about offering hope and personal coping strategies, community linkages, access to a more real world context, psychosocial methods, psycho-education. I think such approaches are really important because it can actually help a person to see that they do not have this awful immovable block of wood that cannot be changed, and life still has all this potential.

The achievements of the this particular local service do help to confirm the truth of what consumers have been saying for years -- that if you treat us well, with kindness and offer us hope, we will get better, we will recover, we will take up the challenges.

So I just want to leave you with a little acronym as a reminder what I have identified as the key ingredient of recovery, as experienced by many consumers.

(Presenter writes on whiteboard the word): H. O. P. E.

(Standing in front of the whiteboard – writing -- and then stepping aside, revealing the words under each letter):

HELP. OUR. POSITIVE. EXPECTATIONS.

I hope you have a really worthwhile discussion and a great process today. Thank you very much everyone.

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