

World Fellowship for Schizophrenia and Allied Disorders

The Concept of Recovery

By Diane Froggatt

In 1991 at the World Federation for Mental Health Congress in Mexico City I conducted a workshop with psychiatric consumers about what factors might be the foundation upon which to build an effective pathway to "Getting your Life Back". We all told our stories and then set about defining the positive things that emerged. No consumer today, nor close family member, would be surprised at what we found, since these findings have been replicated and reiterated in numerous ways both before and since that time. What we might find surprising is how little community mental health services have changed to accommodate these essential components of a relatively good life for people with psychiatric disorders, despite several years' worth of rumblings about "recovery". The essential building blocks for a life regained were:

- Appropriate medical treatment
- Self esteem
- A comfort level about being who we are and acceptance by others of who we are
- A way of being useful
- A feeling of being rooted – a home, loved ones and friends
- Something to inspire us in our lives
- A reasonable standard of living –income

Admittedly, the people who took part in this workshop, like many of the consumers who have been urging a more positive approach to mental illness, were able to enrol in the congress and take part fully in the discussion. Many of their peers in mental illness would not have been able to do this, nor would they be any more able to do so today, because they would need a few more building blocks that would include

Reduction of symptoms such as anxiety, paranoia

Improved cognitive ability

Reduction in real and perceived vulnerability

- Guidance from a close trusted professional or friend

I believe that the people who took part in that international workshop back in 1991 were exceptional people, along with those who have fought from the trenches of schizophrenia to get a better deal than they were dealt from those in the mental health field.

An Historical Perspective

It is sad to relate that evidence-based practices back in the early 1900s offered no hope to people with schizophrenia. Kraepelin and Blueler, the prime researcher-clinicians cited from that time, had only gloom and doom to relate and thus general mental health professionals had no optimistic view to count on. Later, the pendulum swung the other way as Thomas Szasz and R.D. Laing told us that mental illness was a reaction to a sick society and that there was really no such thing. Both views have been overstated and both resulted in a confused mental health force and stigmatized consumers and families.

In the 50s the discovery of the calming properties of chlorpromazine and its application to patients in long-term care in institutions, set in motion the first "recovery movement" which saw this treatment as the panacea that would enable people to live normally outside hospital. Medication proved to be a useful tool in the treatment of mental illness, but it was not the panacea expected for all the patients and left many without care, or homeless in an uncaring community – another factor that was discouraging to mental health professionals, families and consumers themselves.

In 2001 we learned about more positive outcomes for schizophrenia from the substantial results of the World Health Organization International Study on Schizophrenia (ISoS) which examined ICD-10 definition schizophrenia in thousands of patients in many countries. "The overarching message of ISoS," said a report of the study (Harrison, Hopper and Craig, 2001) is that schizophrenia and related psychoses are best seen developmentally as episodic disorders with a rather favourable outcome for a

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significant proportion of patients. Because expectations can be so powerful a factor in recovery, patients, families and clinicians need to hear this. At the same time, the hope these data represent should not be overdrawn. Subjects with poor prognostic indicators were over represented in those lost to follow-up, and mortality was elevated throughout. A relatively modest proportion (about one-sixth) was judged as having achieved complete recovery, in the sense of no longer requiring any form of treatment."

Medications Alone are Not Enough

The introduction of more effective medications, particularly in their side-effect profile, over the last twenty years, has meant that many people who were severely disabled by schizophrenia now experience reduced disability and can look forward to a less restrictive life. Medications, however, have not yet achieved their promise of illness and symptom control, so that to talk in terms of recovery for this particular group is unrealistic, unless we can view it in terms of a process towards the best health possible as described by Liberman (see below).

It would be extremely sad if the enthusiasm and promise for the adoption of a recovery philosophy, somewhat like the enthusiasm of the deinstitutionalization movement 50 years ago, turned out to be a hollow shell - words backed up by few or inappropriate plans, strategies or programmes that again result in disappointments or worse - more people unable to get hospital treatment, and more wandering our streets untreated in any way and without hope. It is up to us to prevent that by creating a climate in mental health systems that leaves opportunity open and supports consumers' needs and wishes.

Courtney M. Harding, in the New York Times (march 10, 2002) wrote:

(People with schizophrenia) improve without fanfare and frequently without much help from the mental health system. Many recover because of sheer persistence at fighting to get better, combined with family or community support. Though some shake off the illness in two to five years, others improve much more slowly. Yet people have recovered even after 30 or 40 years with schizophrenia. The question is, why haven't we set up systems of care

that encourage many more people with schizophrenia to reclaim their lives?

And towards the end of the article she writes: "Now there are renewed calls for recovery-oriented treatment. They should be heeded. We need major shifts in actual practice." Harding does not enlarge upon these in this short article but there are numerous cases of barriers to recovery that the stakeholders have identified that must be removed.

Barriers to Recovery

Dr. Mark Ragins, in his article "Hope and Schizophrenia" (www.village-isa.org) cites one example: the application for (U.S.) government social security benefits which requires the applicant to state that s/he is "permanently disabled". Similarly, WFSAD is aware of cases where a person obtains a job and government benefits are immediately, or within a short time, cut off. If the job does not work out and the person applies to be reinstated, he is told he is able to work and therefore does not qualify for benefits. These are only two examples of practices that we need to change. There are many more such as being unable to qualify for a travel permit or visa; for subsidized housing or for job training. In addition there is the covert discrimination in employment and in many other areas of society.

It is the consumers themselves, who hardly appeared in medical literature until the 90s, who, at considerable cost to themselves, have revealed the societal barriers and the extreme deficits of community and hospital mental health services and government programs. They have told it like it is. And they have told us that it does not need to be this way. What is needed is a groundswell of support for services that respect those who need them, do not abuse their vulnerability, and offer quality programs.

From the struggles of those who were sure there was a better prognosis and therefore a better life, we have arrived at a time when everyone has leapt onto the wagon of Recovery, often with insufficient thought to what such a concept requires. Mental health professionals even talk of the "recovery model" where no model exists. With very little research on what will effect recovery, we must go ahead to fill in the blanks and make it a solidly based reality.

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There are sufficient numbers of anecdotal reports of recovery by exceptional people (for one see Oryx Cohen's report of the oral history of consumers in the *Journal of Humanistic Psychology*, Volume 45, Number 3, 2005). And with the good will and good ideas of mental health professionals mainly in the field of rehabilitation, we are "willing" the possibility of recovery to happen. For some this may seem like a hoax, but for others it is a welcome relief from the depressing picture of poor prognosis and a lifetime difficulties.

Turning the Concept into Reality

So what does it take to make this concept or philosophy of recovery become a reality of effective practice? There is much going on that suggests an effective answer to this question. There are already champions: a large number of active consumers, families and professionals. Then there are government policy initiatives and directives that indicate a desire for this in Australia, the U.K. the Scandinavian countries and the U.S. An example from the U.S. is the National Consensus Statement on Mental Health Recovery of SAMHSA (the U.S. Substance Abuse and Mental Health Services Administration of the Department of Health). This contains 10 "fundamental components of recovery". One of these components is titled "Holistic":

Recovery encompasses an individual's whole life, including mind, body, spirit, and community. Recovery embraces all aspects of life, including housing, employment, education, mental health and healthcare treatment and services, complementary and naturalistic services, addictions treatment spirituality, creativity, social networks, community participation, and family supports as determined by the person. Families, providers, organizations, systems, communities, and society plan crucial roles in creating and maintaining meaningful opportunities for consumer access to these supports.

This one component shows the incredible complexity of the subject. Where should one begin? The other nine components are concerned with empowerment, self-direction; being person-centred, non-linear and strengths-based; including respect, giving responsibility and hope, and providing peer support.

Among the champions are undoubtedly a committed group of mental health professionals who have worked tirelessly to effect better outcomes in social functioning. Their names are familiar in the field: Robert Drake, Robert Lieberman, Gerry Hogarty, Kim Mueser, Nicholas Tarrier and many more, including William Anthony, Director of the Boston Center for Psychiatric Rehabilitation, who has defined recovery as:

A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness (quoted in www.mhrecovery.com).

To accept recovery as a goal, it is essential to be able to devise and set up programs and train staff, and then to be able to measure effectiveness. What might constitute a clinical definition of recovery was outlined by Liberman and Kopelowicz in their article "Recovery From Schizophrenia: A Concept in Search of Research" in the journal *Psychiatric Services*. They were careful to define recovery as a process:

Just as there are clear differences between recovering from alcoholism or drug addiction and having a sustained recovery with long-term abstinence and normal psychosocial functioning, the same holds for recovery from schizophrenia. Many consumers and professionals have confounded recovering with recovery by failing to grasp this distinction. The processes and stages of recovering are preparations for recovery. Characterized by a reliable, normative definition, recovery is an outcome of the process of recovering.

The authors drew attention to a number of studies in different parts of the world that show a high rate of symptomatic remission. A key element in favourable long-term outcomes was access to continuous and reasonably comprehensive, flexible community-based mental health services. In building a construct of recovery for schizophrenia many factors had to be

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considered, from the natural waxing and waning of symptoms common to the illness to symptom remission, to psychosocial functioning, including work, school, family life, friends, recreation and independent living. The authors determined that "Without a methodologically solid social validation, the construct of recovery would suffer from lack of credibility".

Into this mix of what has to happen with governments, champions, researchers, clinicians, families and consumers, is the eternal question of financial support. It is very common in mental health to be asked by government to do more with less. However, with possible structural changes to services to effect better outcomes, functioning and recovery, new funding will be needed. It remains to be seen whether government adoption of policies espousing recovery will enable the funds to flow to those very necessary programs.

Thus we return full circle to the consumer advocacy that first began to tip the balance in favour of a recovery paradigm and will continue to be necessary to convince governments of the rightness of this move. To do this we also need to convince politicians and their constituents that mental illness has been stigmatized too long, and that its under funding has led to demoralization, treatment gaps, chronicity and homelessness.

We now wait for mental health services to catch up with the desires and needs of consumers,

families and their clinicians. We know what our goals are, but none of us is exactly sure how to attain them and through what stages we must pass to bring them closer. It is clear, however, that optimism from all stakeholders and the belief that the goals are possible to achieve, even if over the long term, is essential to counteract the pessimism of previous years.

- So what positive things must we search for that will help us on our way?
- Good clinicians or therapists, who are willing to discuss our hopes and dreams and suggest the steps we might take.
- Peer support groups, found through internet or community contacts
- Skills training to promote our ability to develop and sustain relationships
- Educational programmes that are relevant, of interest and available locally
- A positive attitude from our family and friends
- Regular exercise and diet, combined with care for our physical health
- Courage and determination

The longest journey starts with a single step.

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