

A future with hope



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SCHIZOPHRENIA SOCIETY OF CANADA NEWSLETTER

Why shouldn't we talk about recovery?

Dr. Pam Forsythe, President

As a practicing psychiatrist I am gratified to hear more and more of my mental health professional colleagues talking about "recovery". This concept should be distinguished from a total absence of any signs and symptoms of the underlying illness; rather, it should connote the triumph of a worthwhile life in the face of serious mental illness.



Dr. Pam Forsythe

For too long schizophrenia has been equated with hopelessness, deterioration and isolation, not only for the individual who has been diagnosed, but also often having a similar impact on family and friends - in spite of the evidence that even before the development of pharmacological and other evidence based therapies, a significant proportion of people would actually get better! The challenges and advances of the past 50 years have been to improve the odds that more people will be able to move forward with their life goals even after experiencing a psychotic illness.

At the Schizophrenia Society of Canada, we clearly have a responsibility to impart hope that through research, promotion of effective clinical practices, education and peer support, more and more people will be able to personally speak of their recovery journey. Our voice however is weak – we need to enlist many more people to our cause – families, friends, consumers, professionals and the general public.

Unlike other health causes (breast cancer for example), the schizophrenia movement across Canada lacks cohesion, lacks money and has a very low profile except when there is some catastrophic event involving a mentally ill individual. We struggle with our shared stigma – brave indeed is the person willing to publicly talk about his or her experience as a person with

schizophrenia. Parents may be torn about getting involved with the movement in a public way because their child may not want others to know about his/her condition. In this way we have trouble spreading the word about the success stories – stigma being such a concern that disclosure of past illness could jeopardize someone's continued recovery.

We are currently working to better define what our national focus needs to be: What is the role and function of the national organization? How do we complement and support the provincial and chapter efforts? What organizational structure will enable us to push forward as a schizophrenia movement that is viewed as a credible voice for all the people affected by schizophrenia - consumers/patients, families and friends, citizens concerned with social justice? The Board of SSC, ably assisted by Tim Feher, our organizational consultant and Chris Summerville, our Interim CEO, is working with the provincial societies to clarify this mandate. We want to have a plan to present to our constituents in the fall.

We have a lot of work to do and would welcome input from you all. We believe that there is a significant opportunity to build on the momentum that has been created by the establishment of the Mental Health Commission of Canada – we need to be part of that dialogue with Canadians about the importance of mental health issues for us all. ■

"The most common identified factors in recovery definitions are: reduction in psychotic symptoms, medication use (or non-use), participation in valued activities and social roles, constructing meaning from the experience, rebuilding a positive identity and the development and use of personal resources (agency) in promoting and maintaining gains."

– Deborah L. Windell, Dr. Ashok K. Malla & Ross M.G. Norman

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What is Quality of Life?

Message from SSC Interim CEO, Chris Summerville

Last year the Schizophrenia Society of Canada (SSC) unveiled a new mission statement which focuses on “improving the quality of life for those affected by schizophrenia and psychosis through education, support programs, public education and research”. This new mission statement indeed opened up broader ways for the Society to support people as they move towards recovery.

Whereas the previous mission statement seemed to restrict us to “alleviating the suffering of schizophrenia” through the necessary biomedical intervention, the new mission statement emphasizes quality of life. Embedded within the term “quality of life” is a much more holistic approach that emphasizes body, mind and spirit in the context of community. We know that quality of life is more than not having symptoms of illness or staying out of hospital. In fact, recovery is more than symptom reduction. A person may well be taking medication faithfully, but not living a life of quality or of recovery!

The provincial schizophrenia societies will be working with the Schizophrenia Society of Canada in conducting a national survey on quality of life for those affected by schizophrenia and psychosis. “Not



Chris Summerville

only will it assist us in knowing how to live out our mission statement, but it will give us ideas as to the issues we should be advocating for both provincially and nationally,” says Florence Budden, Chair of the Public Policy and Advocacy Committee of SSC. The survey will be conducted from June to the end of August.

If you have lived the experience as a consumer or as a person providing support to a family member / loved one living with schizophrenia, or a psychotic disorder, we are interested in knowing what quality of life means to you? By psychotic disorder we are referring to losing touch with reality, experiencing hallucinations, and delusions (fixed false beliefs) that affect thinking and mood.

Surveys are confidential. It will take about 15 minutes to complete. When completed please return to your provincial schizophrenia office or mail back to the address below. There are two surveys: one for consumers and another for families, friends and caregivers.

In English

An on-line copy of the CONSUMER SURVEY is available at:
http://www.surveymonkey.com/s.aspx?sm=XM_2b_2bNoos0nPrzE_2fVcDU1kA_3d_3d

The on-line copy of the FAMILY / FRIEND / CAREGIVER SURVEY is available at:
http://www.surveymonkey.com/s.aspx?sm=VRhX5owBSrUjGEL5ZSkqfw_3d_3d

In French

An on-line copy of the CONSUMER SURVEY is available at:
http://www.surveymonkey.com/s.aspx?sm=axXLRvwhLbc8HTCRR_2b_2fsjg_3d_3d

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http://www.surveymonkey.com/s.aspx?sm=zNJTDXbWpNhbnlyl0EX5sIA_3d_3d

I am looking forward with great anticipation to the final report of the research project which is being administered by Neasa Martin of Neasa Martin and Associates. Neasa has extensive and broad experience within the mental health movement and is currently engaged in several projects with the Mental Health Commission of Canada. She will be presenting a summary of the results of the research in October during Mental Illness Awareness Week in a meeting hosted by the SSC. The report will be made available through the SSC website.



“Don’t tell me that recovery is not evidence based – I’m the evidence!” – Woman with a serious mental illness

Quality of Life and Recovery

The following are excerpts from a presentation entitled "The Role of Collaborative Care in Rehabilitation and Recovery" by Chris Summerville, D.Min., CPRP who is Interim CEO of the Schizophrenia Society of Canada. The plenary presentation was given at the 2008 National Conference on Collaborative Mental Health Care in Victoria, British Columbia on May 16, 2008.

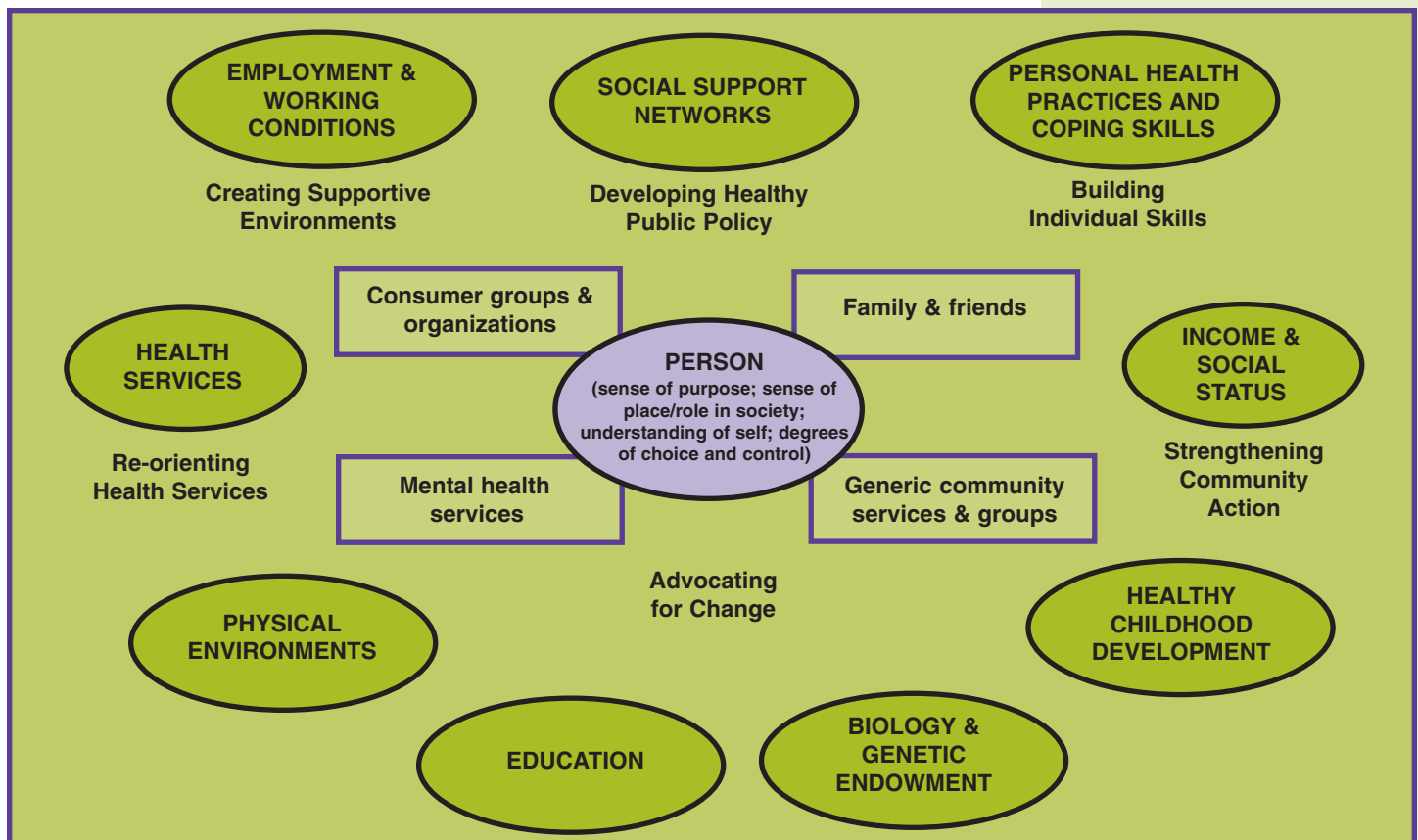
The concept of recovery is not new and has been used by people with a mental illness since the 1980's. As a service model it has been gaining prominence outside of Canada for the last 20 years as a guiding principle for mental health services. The concept of recovery has become a key aspect of mental health policy in many Western countries. This is especially true in New Zealand, Australia, England, Scotland, Ireland and the United States where mental health legislation and policy have adopted the recovery model.

As a philosophy, paradigm, and model the concept of recovery has evolved from the lived experience and writings of people who use mental health services (Deegan, 1988, Houghton, 1982; Leete, 1989; McDermott, 1990; Unzicker, 1989). "It is a concept that has attracted considerable enthusiasm and hope in an area often characterized by disillusionment and defeat. It presents all of us involved in mental health services with the challenge and opportunity to work together and to integrate our various skills and experiences." (A Common Purpose: Recovery in Future Mental Health Services Royal College of Psychiatrist, 2007)

You will note that I said that the recovery model has been gaining prominence outside of Canada. Truth of the matter, health care providers have not been talking seriously about recovery in Canada until recently! In fact we service providers have a difficult time discussing the concept, much less using the word or practicing it! These concerns were pointed out in an article in Psychiatric Services (Psychiatr Serv 59:446-447, April 2008). The author states:

"We believe that the results of this study speak to the need for mental health providers to better understand recovery principles, learn to work from a recovery perspective, and empower consumers to take responsibility for their own recovery. This process starts when providers use the word themselves. The recovery vision will not easily take hold among consumers in the current Canadian context unless providers integrate the word "recovery"—and a belief in what the word implies—into their practice."

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From, "Mental Health Promotion For People With Mental Illness - A Discussion Paper" for Mental Health Promotion Unit of The Public Health Agency of Canada - April 2002

Quality of Life and Recovery

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The article goes on to recognize a Canadian multi-site, qualitative study of stakeholder perspectives on recovery conducted in 2006–2007. Eighty-six percent described themselves as being in recovery but 69% declined to use the word when speaking with other people. Only 21% used the word with others. On the question about consumers' sources of information on recovery, service providers were named as a source by only 40% of the respondents. Another 41% indicated that consumers had no sources of information before this study or that they had investigated recovery on their own. Nineteen percent identified peers as the source of information on recovery.

Most disturbing to me are the number of mental health service providers who do not believe that recovery is possible. But even more alarming is the number of consumers I meet who have been told they will never recover from mental illness.

One of the values and beliefs of the work of the Mental Health Commission of Canada is: *"A focus on recovery and hope to enable people living with mental health problems and mental illness to lead meaningful and productive lives consistent with the limitations imposed by their illness."*

What is recovery? Although there is no universal consensus among service providers, consumers will tell you what it means to them if you ask them! To understand what recovery is, it is helpful to understand first what the person with mental illness is often recovering from. Cheryl Gagne with the Psychiatric Rehabilitation Center of Boston University offers the following:

- Loss of self, connection and hope.
- Loss of roles and opportunities.
- Devaluing and disempowering programs, practices and environments.
- Prejudice and discrimination in society.
- Internalized oppression and shame.

Recovery from the consequences of the illness, as well as a non-recovery oriented mental health system, is sometimes more difficult than recovering from the illness itself! What consumers are looking for is HOPE. Can one recover from these various losses? Indeed, they can!

"Consumer-focused recovery is important because it represents "a way of awakening hope, restoring lost dreams and building optimism." Recovery does speak to the impairment caused by psychosis. But it also addresses the dysfunction that results in the inability to perform certain tasks. It acknowledges the disability that can lead to unemployment and homelessness. Recovery does speak to the disadvantages of discrimination and poverty." (Anthony, Cohen & Farkas, 1990)

Although medication can provide assistance with symptom relief on which recovery is built, there is no medication that can restore the profound losses experienced by those with mental illness. No antipsychotic can reduce stigma and discrimination, provide you with safe-affordable housing or give you meaningful work. No antidepressant can give you meaning, hope and purpose or substitute for psychological support services to address unresolved trauma. No benzodiazepine can undertake stress management and conflict management for you or restore lost personal goals. There are no neuroleptic medications that can create a person centered approach or do all that a recovery-oriented mental health system can do.

What is the goal of recovery? Quality of Life!! This is more than maintenance or stability. Dr. Stephen R. Marder, MD who is Professor and Director of Section on Psychosis at the University of California at the Los Angeles Neuropsychiatric Institute says,

"I think a recovery model has a number of components. First of all, the focus of treatment isn't just on stabilizing the patient in his or her current condition, but on having that patient improve the quality of his or her life. In the past, the focus of treatment by psychiatrists was on controlling symptoms so that patients could remain in the community and not be hospitalized. But patients and families are saying the control of symptoms is really less important than improving function. Patients are asking to be able to return to work, to return to school, and even are suggesting that psychiatrists may be underestimating the ability of people with schizophrenia to function in the community." (Medscape Psychiatry & Mental Health, March 2005.)

Another way of seeing recovery goals is from the clinical, functional and existential perspectives of personhood. Clinically, recovery goals involve: access to services, symptom reduction, symptom management, improved functioning, less rehospitalization, and less relapse.

Functionally they are: a renewed self-esteem, going back to school, being gainfully employed, social connectedness, living independently, support from others, making informed choices, no involvement with the criminal justice system, and taking responsibility.

Existentially and spiritually the goals of recovery are: renewed purpose, meaning and hope.

"There seems to be three domains of recovery that have emerged as the concept has developed: personal recovery, social recovery and illness recovery." (Windell, Malla and Norman, 2008).

Personal recovery involves the transformation of the meaning of the illness and a positive sense of identity. Reconstruction of a new identity is crucial in recovery. It is coming to terms with

losses and regaining a sense of self worth and hope. It is a recovery of purpose and meaning.

Social recovery has to do with roles, relationships and social worth. Here the person regains social competence and active participation in valued roles and relationships. Social inclusion is a goal of recovery.

Illness recovery is managing ones illness with elimination or diminishment of symptoms.

Dr. Mark Ragins is a recovery-oriented psychiatrist who is Medical Director at The Village in Los Angeles. Dr. Ragins works with people who are often referred to as having a "severe and persistent mental illness" like schizophrenia. He says that mental health services and interventions must be person centered rather than illness centered:

"The goal of our services is not to treat illnesses, but to help people with serious mental illnesses have better lives. For example, when we give someone medication it's not to reduce voices; it's to help them get a girlfriend or keep their job. We focus not on illness based outcomes, like symptom relief, but on quality of life outcomes, like improved housing, employment, education, finances, health care, social life, and families, while avoiding legal problems, drug abuse problems, hospitalization, and homelessness. These goals are socially valued, but individually determined, based on each person's choices. Services, including, but not limited to, treatment and rehabilitation, are goal driven, not symptom driven." ("Person Centered Vs. Illness Centered," 2006).

Dr. Larry Davidson, professor at Yale University would have health care providers ask themselves the following questions: "If what you are offering is not oriented to promoting recovery, then what is it for? If there is no evidence supporting the effectiveness of a given practice in promoting an individual's ability to manage, overcome, or live with his or her mental illness, then why should scarce resources be used to fund it? If there are ways in which what you offer could be more recovery oriented, and thereby more effective at achieving its aims, would you not want to try to learn about it and try it?"

Yes, mental health services and providers play a critical role in facilitating and supporting people in the recovery process. Your job is to ask people living with mental illness what it is that they want and need in order to grow. Then you create an environment that facilitates that growth. Again Pat Deegan says it so succinctly:

"It is not our job to pass judgment on who will and will not recover from mental illness and the spirit breaking effects of poverty, stigma, dehumanization, degradation and learned helplessness. Rather, our job is to participate in a conspiracy of hope. It is our job to form a community of hope which surrounds people with psychiatric difficulties."

Martin Luther King in his "Letters from a Birmingham Jail", writes about the white clergy who asked him to delay his protest marches. To this plea, King had the following response:

"We know through painful experience that freedom is never voluntarily given by the oppressor; it must be demanded by the oppressed. Frankly, I have yet to engage in a direct action campaign that was 'well trimmed' in view of those who have not suffered unduly from the disease of segregation. For years now I have heard the word "Wait!" It rings in the ear of every Negro with piercing familiarity. This "Wait!" has almost always meant "Never." We must come to see, with one of our distinguished jurists, that justice too long delayed is justice denied."

We can't wait any longer in developing a recovery-oriented mental health system in Canada!

"If we are serious about the vision of recovery, then the mental health system of the last century, which for the most part was a system characterized by low expectations- , control, and no consumer-based voice or vision, must disappear. Massive system changes must occur if the vision of recovery is to become a reality for an ever-increasing number of people with sever mental illnesses. For this very different vision to become reality, brilliant leadership is required."(NASMHPD/NTAC e-Report on Recovery, Fall 2004). ■

"We must keep alive the hope that recovery is possible. There is reason to hope! Half to three-quarters of those with schizophrenia recover. This does not mean that they are cured or that the illness goes into complete remission, although this has happened in some instances. It means that over time, in an often long, difficult process, individuals come to terms with their illness. They learn how to accept it and then how to move beyond it, to believe in every cell of their being that they are not 'schizophrenic', defined solely by an illness. They are individuals, whole and complete in themselves, with strengths as well as limitations, with the capacities to love and be loved, to work and find joy and meaning in their lives despite an illness." – Finding Hope in Schizophrenia: Healing and Hope for Everyone in the Family – Louise Loots Thornton

SSC Announces New Resources in Addressing Mental Illness and Substance Use

Half of all people living with schizophrenia will experience a substance use disorder in their lifetime, creating a complex set of challenges for them, their families and the health professionals who treat them.

While gains are being made in the treatment of co-occurring schizophrenia and substance use problems, much of this information is not making its way to the community level, resulting in limited resources and information being available to individuals and families.

With the launch of the Schizophrenia and Substance Use initiative, the Schizophrenia Society of Canada is addressing the need for centralized, up-to-date, Canadian-based information and resources for service providers, consumers, family members and youth.

"We want to make families, service providers and people living with mental illness aware of the need for addressing substance use by those with a mental illness. Both the mental illness and substance use must be treated simultaneously as one impacts the others. Failure to do so results in delayed or failed recovery. These new materials and web site bring important attention to the relationship between mental illness and substance use," says Chris Summerville, Interim CEO of the Schizophrenia Society of Canada

One of the first steps in the project, launched in September 2005, was to

develop a pan-Canadian concurrent disorders panel, comprised of treatment professionals in the fields of mental health and addictions, administrators, researchers, and people with schizophrenia and their families. This panel provided leadership and direction throughout the project.

Dr. Stan Kutcher, Sun Life Chair in Adolescent Mental Health at Dalhousie University, and a member of the project's advisory panel, emphasizes that the information generated by the project will be helpful for many different groups, given that "problem substance use may be the rule rather than the exception for many people with mental illness, and in particular for young people struggling with the symptoms of psychosis. Effectively addressing that issue is necessary in order to enhance outcomes and to promote recovery."

During the first year of the project, six cross-Canada consultations were held which brought together individuals and family members affected by concurrent disorders, treatment professionals, researchers and administrators. The purpose of the consultations was to acquire expertise from the various sectors across the country and identify regional resources, service delivery gaps, then recommend solutions to advance the issue of concurrent substance use disorder and schizophrenia.

The findings were used to develop a discussion paper which highlighted best practices, as well as the gaps and needs faced by family members, consumers and service providers from different regions across Canada.

In response to the need for public information, repeatedly emphasized during the consultations, SSC developed these public education materials that were launched during Mental Health Week, May 5 – 9, 2008. In addition to making clear, accessible information available about schizophrenia and substance use to consumers and families, the website can also "act as a portal for ongoing information sharing and networking, and can provide a venue for posting information on emerging best practices and evidence-informed approaches", comments Wayne Skinner, Deputy Clinical Director, Addictions Program, at the Centre for Addiction and Mental Health, and member of the project's advisory panel.

To view and download the project materials, please refer to the website at www.schizophreniaandsubstanceuse.ca



"Recovery is not necessarily the absence of symptoms, but instead it is moving beyond the symptoms of the illness and side effects of the medication to live the life we want and deserve."

– Roy Muise, Peer Support Specialist

Recovery - Paradigm Shift or Shibboleth?

Larry Davidson, Ph.D., Professor of Psychiatry, Yale University

So What is Recovery

After an exhaustive (or at least very tiring) search of the literature and reflection on first person accounts, we came up with the following:

Recovery involves a process of restoring or developing a meaningful sense of belonging and positive sense of identity apart from one's disability and then rebuilding a life in the broader community despite or within the limitations imposed by that disability.

Defining Our Terms

Recovery refers to the ways in which a person with a psychiatric disorder manages his or her disability in the process of reclaiming his or her life in the community.

Recovery-oriented care refers to what psychiatric treatment and rehabilitation practitioners offer in support of a person's recovery.

Sample Dimension from Recovery Model - Being Supported by Others

Person In Recovery:	Direct Service Provider:	Manager:	Recovery Markers:
<i>To me, recovery means...</i>	<i>I can support people in their recovery by...</i>	<i>I can lead an organization that supports recovery by...</i>	<i>We will know that we are working together toward recovery when...</i>
<ul style="list-style-type: none"> • having people I can count on • being loved and accepted as I am • having people in my life who believe in me even when I don't believe in myself • having something to give back • feeling like a worthwhile human being • being able to help others when they need me 	<ul style="list-style-type: none"> • helping people to develop lasting connections to communities and natural supports • being willing to include these natural supports in the recovery planning process • being willing to help people get their basic needs met in the community, e.g., managing benefits and finding financial resources, food, shelter, and safety • believing in people and sharing that belief with others • being an "advocate" as well as a "provider" • valuing and exploring spirituality as a potentially critical source of support 	<ul style="list-style-type: none"> • educating staff and others about natural support networks and how to build them • developing structured educational programs for families and members of natural support networks • offering to host local, regional, statewide, and national consumer and family support services • valuing and fostering use of peer-support and self-help throughout the agency 	<ul style="list-style-type: none"> • staff help build connections with neighborhoods and communities • services are provided in natural environments • peer support is facilitated and utilized • natural supports are relied upon <p style="text-align: right; font-size: small;">Tondora, Davidson, O'Connell, Sangster & Fry (2004)</p>

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Recovery - Paradigm Shift or Shibboleth

Larry Davidson, Ph.D., Professor of Psychiatry, Yale University

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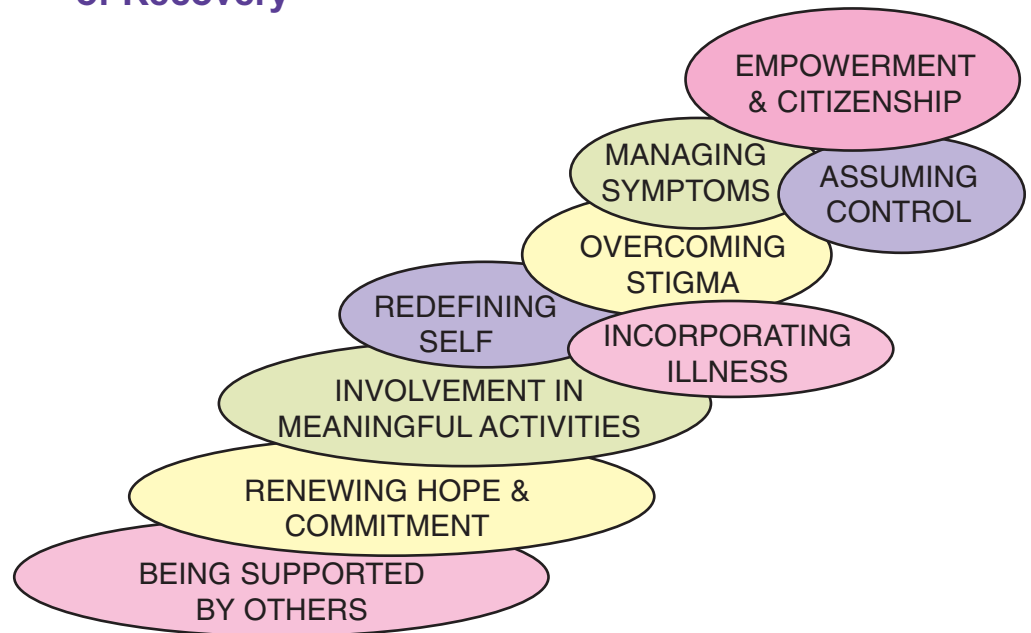
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Building Blocks of Recovery



"A recovery vision is not a function of one's theory about the causes of mental illness. Recovery can occur regardless of the 'cause'. The key element is that there is hope for the future, rather than understanding the cause in the past."