Network

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Recovery: the emergence of new life from the depths of winter

CANADIAN MENTAL HEALTH ASSOCIATION
L'ASSOCIATION CANADIENNE POUR LA SANTÉ MENTALE
Ontario Division/Division de l'Ontario

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Shaping a Recovery Philosophy

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OUR MISSION:
To provide leadership in advocacy and service delivery for people with mental disorders, and to enhance, maintain and promote the mental health of all individuals and communities in Ontario.

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A symbol of resilience and recovery for people who care about mental illness and health.

What are people recovering from?

This issue of *Network* discusses recovery from mental illness with three viewpoints in mind: How researchers define recovery, how a person describes her personal journey and what difference adopting a philosophy of recovery might make for an entire service system.

Exactly what people are recovering from requires some careful thought. Here are some of the answers I have read about or heard from people who have experienced a mental illness.

A psychotic break: This is the epitome of mental illness. It can signal the onset of schizophrenia or can be part of depression or bipolar disorder. The experience of losing one's mind is described as tantamount to losing one's self. Once the person is stabilized, he or she now knows that the mind can be a traitor. Thoughts and perceptions are no longer trusted and firmly held beliefs are exposed as false, sometimes humiliatingly so.

A history of childhood trauma: The second event is the experience of childhood trauma – sexual and physical abuse, neglect or abandonment, usually within the family context. Child abuse envelopes the whole of the selfhood of a person. The result, in adolescence or adulthood can be a diagnosis of mental illness which may include borderline personality disorder and/or depression.

In addition to the tragedy of mental illness, people say that they have to recover from the consequences of the diagnosis.

Iatrogenesis: This term is used to describe the harm caused by medical interventions that were supposed to alleviate symptoms. Instead of being helped, many people, calling themselves psychiatric survivors, say that the mental health system harmed them and recovery can occur only through openly expressing anger, engaging in political protest, and in seeking fellowship among peers who share their views.

Disability: Until the advent of psychosocial rehabilitation, it was uncommon for people with mental illness to be called disabled. Access to needed resources comes through accepting a designation of long term impairment which, in effect, creates the social category of "psychiatric disability." Entering the role of disabled carries with it admittance to such valued services as subsidized housing, case management, and employment programs but it is also associated with negative social consequences that can include marginalization and isolation.

Helplessness and hopelessness: Learned helplessness is defined as a deep despair that comes from repeated or prolonged institutionalization. Along with helplessness comes hopelessness where people receive repeated messages aimed at persuading them they have a debilitating illness that will never improve. Mental health professionals can inadvertently reward learned helplessness because clients who do as they are told are considered easy to manage. They may also contribute to hopelessness by defining "insight" as the capacity to accept a bleak prognosis. Conversely, people who are actively engaged in their own recovery ask probing questions, challenge treatment decisions, protest loudly if they feel wronged, and generally take on a more egalitarian adult role in the management of their own well-being.

Discrimination: People who have been diagnosed with a mental illness are all too aware of the negative social stereotype they now occupy. Confiding in friends may mean that they no longer call and family members may hide the fact that a loved one is ill because of shame. They may be denied housing or the chance of employment if their diagnosis is known. People are also subjected to bigoted name calling and the media continually portrays them as dangerous. The social isolation that results impedes recovery and, given that people with mental illness are members of the same culture that stigmatizes them, they often internalize negative stereotypes and convert them into self-blame, an attitude which affects recovery because people come to expect devaluation and rejection.

Given the many challenges that people with mental illness face, recovery is a complicated journey composed of many things but, most of all, courage.

BARBARA EVERETT, PH.D.
Chief Executive Officer

Recovery: A Changing Environment

In an address given by Patricia E. Deegan, Ph.D. at The Sixth Annual Mental Health Services Conference of Australia and New Zealand, she compares the journey towards recovery, undertaken by someone with a mental illness, to that of the cycle of the seasons: for nature to finally bloom again after the dead of winter, the surrounding environment has to change.

For those with mental illness, there is hope that the grip of winter is finally easing. The belief that certain diagnoses meant inevitable deterioration is changing. The consumer/survivor movement has given voice to the journey of recovery as stories are shared and hope, healing and empowerment take hold in individuals' lives. But what do we mean by 'recovery'? How do we design and implement systems that support it? How do we measure the success of new initiatives and programs? Most importantly, how do we ensure that the changes are substantial and not merely cosmetic?

For those of us who have been diagnosed with mental illness....hope is not just a nice sounding euphemism. It is a matter of life and death...... We have known a very cold winter in which all hope seemed to be crushed out of us. It came like a thief in the night and robbed us of our youth, our dreams, our aspirations and our futures. It came upon us like a terrifying nightmare that we could not awaken from.

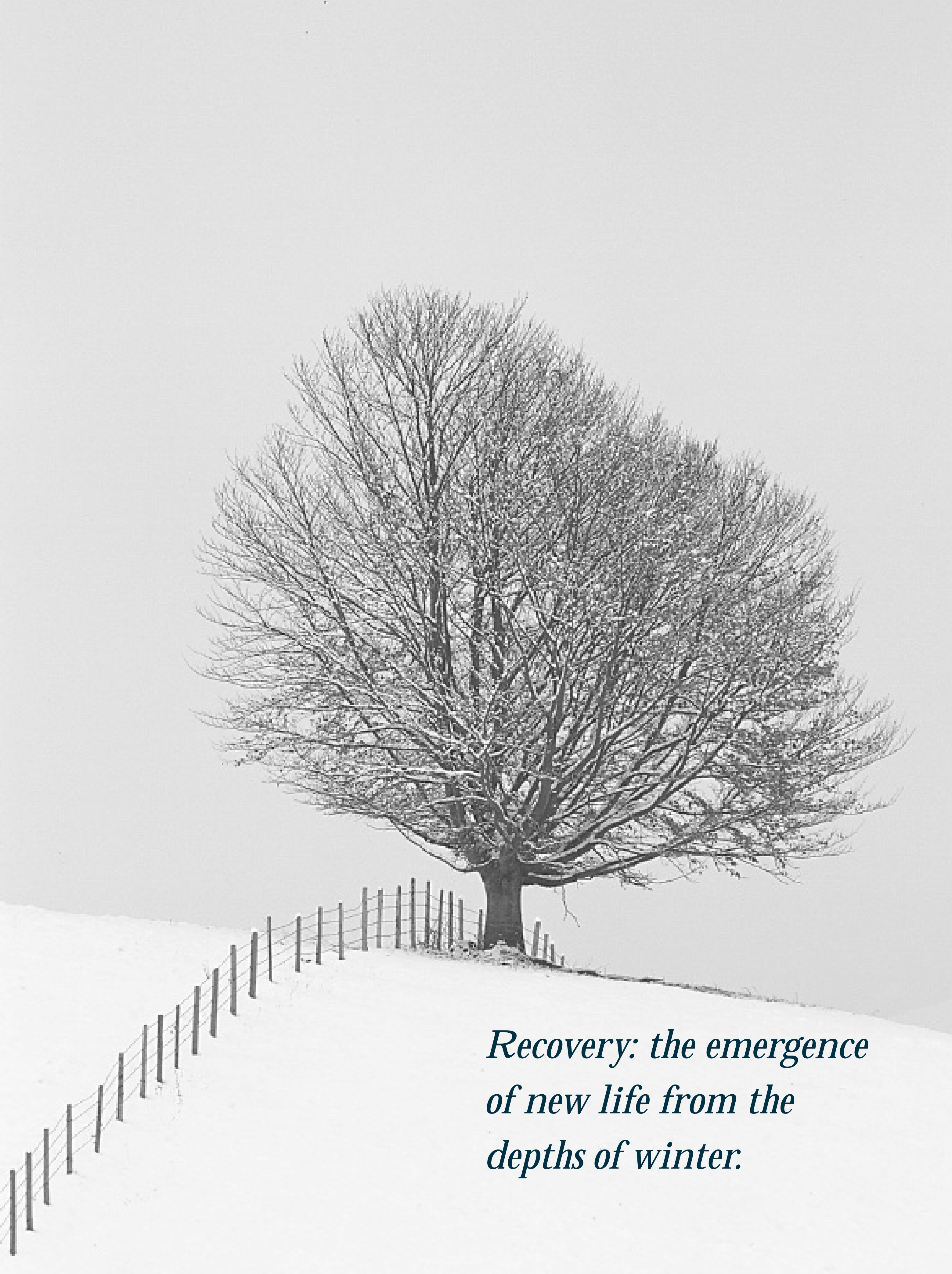
Patricia E. Deegan, Ph.D.

In this issue of *Network*, Dr. Nora Jacobson gives insight into the complexity of defining recovery, and how that definition changes in relation to the individual, the organization and the system.

In an interview with Jean Johnson we learn that from a consumer/survivor's perspective the journey of recovery is ongoing. It is defined by a belief in one's self and nurtured by the respect and compassion of good friends and companions along the way.

The nine regional Mental Health Implementation Task Forces have adopted the recovery philosophy as a 'driving fundamental value' (The Hon. Michael Wilson) in all of the research and consultations that have been conducted over the past two years. Mr. Wilson talks about this philosophy, and the report which will be presented to the Minister of Health and Long Term Care, beginning on page 15.

Dr. William A. Anthony, Executive Director of the Center for Psychiatric Rehabilitation at Boston University, has described recovery as 'a way of living a satisfying, hopeful and contributing life even with limitations caused by illness.' In Ontario, interest in having a recovery-oriented mental health system is widespread, the challenge is now to learn more from our own experience and the experience of others as we strive to make this happen.


Recovery: the emergence of new life from the depths of winter.

Defining Recovery

Nora Jacobson is a Research Scientist, Health Systems Research and Consulting Unit, Centre for Addiction and Mental Health (CAMH) and Assistant Professor, Department of Psychiatry, University of Toronto. Dr. Jacobson completed an NIMH-sponsored postdoctoral fellowship Mental Health Services Research Training Program a University of Wisconsin-Madison. In 1997 she was the American Sociological Association's Spivak Program Congressional Fellow, working as a health policy fellow for Senator Edward M. Kennedy and the Senate Labour Committee. An interpretive social scientist, Dr. Jacobson uses qualitative methods to study the ways in which social constructions of health and illness affect the making of health policy and the delivery of health services. Some of her current work examines how the co recovery has been constructed by different stakeholders a how these constructions are made manifest in policy an practice. She has recently completed a book-length manuscript that explores many of the ideas raised in this conversation.

Dr. Jacobson, perhaps we could start off by trying to define what we mean when we talk about recovery as it relates to mental health.

NORA JACOBSON: Recovery means many different things: there isn't any one recovery model. First of all there is a level of recovery that is about what happens in the lives of individuals – their experiences of hope and meaning. Then there is a level that has to do with the service organizations that support individuals in their recoveries. Finally, there's the systemic level – the policies that have to be in place to support a recovery-oriented system.

"People who have psychiatric disabilities often find that they lose their 'selves' inside mental illness. Recovery is in part the process of 'recovering' the self by reconceptualizing illness as only a part of the self, not as a definition of the whole."

NORA JACOBSON, PH.D., DIANNE GREENLEY, M.S.W., J.D.:
What is Recovery? A Conceptual Model and Explication.

So would it be true to say that recovery is a process as much as it is an outcome?

NORA JACOBSON: Yes, very true, but let me preface what we are talking about by saying that as with everything in recovery there are many different versions; what I am describing to you is my interpretation. The way I think about this, and the way I present it when I speak to groups, is that recovery is the solution to a problem and people think about this problem on one or more of the three levels – individual, organizational, systemic – that we spoke about. At the same time you have two ways of looking at these three areas. One is to see recovery as a kind of mental health reform and the other is to see recovery as a kind of transformation. So in fact I believe there are at least six possible interpretations of recovery. For example, at the individual reform level the problem recovery is meant to solve is what we call mental illness. If you move to the individual transformation position, the problem is one of marginalization, discrimination and prejudice against people who are different. If you're looking at recovery on the organizational level from a reform perspective, the problem being solved is chaos in the mental health system – lack of funding, lack of good planning, an inability to implement the practices that evidence suggests work and so on. When you arrive at the systems level transformation position, mental illness doesn't exist – a more radical idea – and it is society itself that has to recover. So you can see that people mean a whole bunch of things when they talk about recovery – everything from recovery being the logical result of implementing best practices and ensuring that all individuals have access to the best care, to recovery meaning that we have a socially just world.

Recovery then would be unique to each individual?

NORA JACOBSON: Yes, and it would be unique in two ways. Experientially, every individual who has been diagnosed with a mental illness has different hopes and dreams, so recovery is different in that way. It's also unique because even when you have a group of people in the room who are talking about

INDIVIDUAL

REFORM POSITION	**TRANSFORMATION POSITION**
Recovery = **the solution to the problem that we call mental illness.**	***Recovery*** = **the solution to the problem of stigma and discrimination in society towards those who are different.**

ORGANIZATIONAL

REFORM POSITION	**TRANSFORMATION POSITION**
Recovery = **the solution to the problem of lack of funding, housing, etc.**	***Recovery*** = **the solution to the problems created by mental health services.**

SYSTEMIC

REFORM POSITION	**TRANSFORMATION POSITION**
Recovery = **treating mental illness like any other physical disorder.**	***Recovery*** = **acceptance of the more radical idea that mental illness doesn't exist – society needs to recover.**

Consumers and professionals who accept the dictionary definitions of recovery – to regain normal health, poise or status – may resist the very possibility of recovery because they see it as an unrealistic expectation. However, it is important to remember that recovery is not synonymous with cure.

What Is Recovery?
A Conceptual Model and Explication
NORA JACOBSON, PH.D., DIANNE GREENLEY, M.S.W., J.D.

Defining Recovery

a recovery model they are often coming from a different perspective with different definitions of the problem.

Surely this makes it extremely difficult then not only to develop a recovery model, but having done so to measure recovery?

NORA JACOBSON: Definitely, and the two really exciting parts of this whole recovery endeavour right now are first of all what do you do to implement recovery on an organizational level and, because organizations are so accountability minded, how do you measure it? How do you know if an organization is recovery-oriented?

> *"Recovery is the process by which people with psychiatric disabilities rebuild and further develop... important personal, social, environmental and spiritual connections and confront the devastating effects of stigma through personal empowerment. Recovery is a process of adjusting one's attitudes, feelings, perceptions, beliefs, roles and goals in life. It is a process of self-discovery, self-renewal and transformation. Recovery is a deeply emotional process. Recovery involves creating a new personal vision for oneself."*
>
> LEROY SPANIOL, MARTIN KOEHLER, DORI HUTCHINSON
> *The Recovery Workbook*

Can you give a brief history of how this fairly modern idea of recovery has evolved?

NORA JACOBSON: I trace it back to three phenomena. The first is the consumer/survivor movement, an explicitly political social movement that contains critiques of psychiatry and mental health services and that seeks to promote individual empowerment. You'll recognize many of their ideas in the transformation position. The second is the psychiatric rehabilitation model, which thinks about mental illness as a disability and seeks to help individuals do better by teaching them specific skills and strategies. The third is the body of longitudinal research, particularly the work done by Courtenay Harding and her colleagues in Vermont, that has suggested that even patients from the "back wards" of hospitals, diagnosed with schizophrenia, have a variety of outcomes if you follow them over a long period of time. These three phenomena are what I see as the sources of the idea of recovery that people have been talking about recently.

> *"[Recovery] means a kind of readaption to the illness that allows life to go forward in a meaningful way. The adaptive response is not an end state. It is a process in which the person is continually trying to maximize the fit between his or her needs and the environment."*
>
> AGNES B. HATFIELD AND HARRIET P. LEFLEY
> *Surviving Mental Illness: Stress, Coping and Adaptation*

What conclusion do these three phenomena lead us to regarding recovery?

NORA JACOBSON: Together, they suggest that people can get better, that a diagnosis does not mean inevitable deterioration, that there are ways in which services can be designed to help people lead more meaningful lives, and that even the most marginalized people can empower themselves. I think the first person to use the word recovery in this sense was Patricia Deegan in 1988.

Presumably there needs to be certain services and standards in place in the mental health system to create an environment that will help nurture recovery in individuals?

NORA JACOBSON: Of course this is true. Deegan talks about the ways in which we can work towards environments that nurture recovery. A 1993 paper by William Anthony is much more explicit about this issue. He writes that recovery should be the standard in the mental health system. In this article, and his later work, he develops a model that aims to combine psychiatric rehabilitation with community support services in such a way as to meet people's multiple, complex needs and promote recovery.

What do you think services in the mental health system in Canada are currently geared towards?

NORA JACOBSON: My first reaction is that probably different services are geared toward different things. A second response would be my impression that in Ontario recently there has been so much upheaval around the funding of services that a lot of what they are about is just survival. Surviving as organizations; surviving as individual providers in a very difficult situation. Something I always say when I talk to audiences of service providers is that I think most people who enter the mental health field do so because they have an idea of hope. They really want to make a difference, to help people find ways to improve their lives. For many reasons, that gets beaten out of them along the way. So a lot of what needs to happen with recovery is for service providers to be empowered, as well as clients.

"To me, a recovery paradigm is each person's unique experience of their road to recovery. There are similarities around themes or shared skills and experiences, but it is in fact a very individual experience which is not possible to etch in stone. It is more the embracing of the belief that recovery is possible and from that premise each person individually creating their own journey."

AMY K. LONG: *Reflections on Recovery*

Could you talk about the paper you co-authored entitled What Is Recovery? A Conceptual Model and Explication?

NORA JACOBSON: The basic idea is that when people use the word recovery they are referring both to the individual, internal experience I've mentioned and to the external environment that supports the internal experience. What the conceptual model does is lay out the elements of both the internal and the external. The paper actually seems to have nailed down the idea of recovery a bit more than I'm comfortable with – it's called *A* Conceptual Model and people often ask me to speak about *The* Conceptual Model!

"[Recovery is] 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 illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness."

WILLIAM A. ANTHONY: *Recovery from Mental Illness: The Guiding Vision of the Mental Health Service System in the 1990s*

What do you think should be recommended and implemented in the mental health services sector to ensure we become recovery-oriented?

NORA JACOBSON: I'm going to sidestep that question somewhat. I'm not a clinician. I'm not an expert on services. I've only just started doing some work to look at what this means for service providers so I don't feel comfortable saying what should be implemented. What I do think is key for organizations, and what I do feel comfortable saying, is that really being recovery-oriented means making structural changes at the level of mission, at the level of rules and regulations, at the level of incentives. It's not a surface phenomenon. For example, one of the implications for providers working within a recovery framework that defines recovery as a matter of autonomy, is to make sure that we are not at the same time holding providers responsible for the autonomous choices that clients make. When people are responsible for others' choices it's only natural that they are going to try to get them to make what they themselves perceive as the *right* choices. I guess my response to your question is that the mental health services sector has to do some work to define what it means by recovery, and then ensure that the structures in place are consistent with that definition.

An analysis of numerous accounts by consumers of mental health services who describe themselves as "being in recovery" or "on a journey of recovery" suggests that the key internal conditions in this process are hope, healing, empowerment and connection. The external conditions that define recovery are human rights, "a positive culture of healing" and recovery-oriented services.

What Is Recovery? A Conceptual Model and Explication

NORA JACOBSON, PH.D., DIANNE GREENLEY, M.S.W., J.D.

THE ROAD TO RECOVERY:

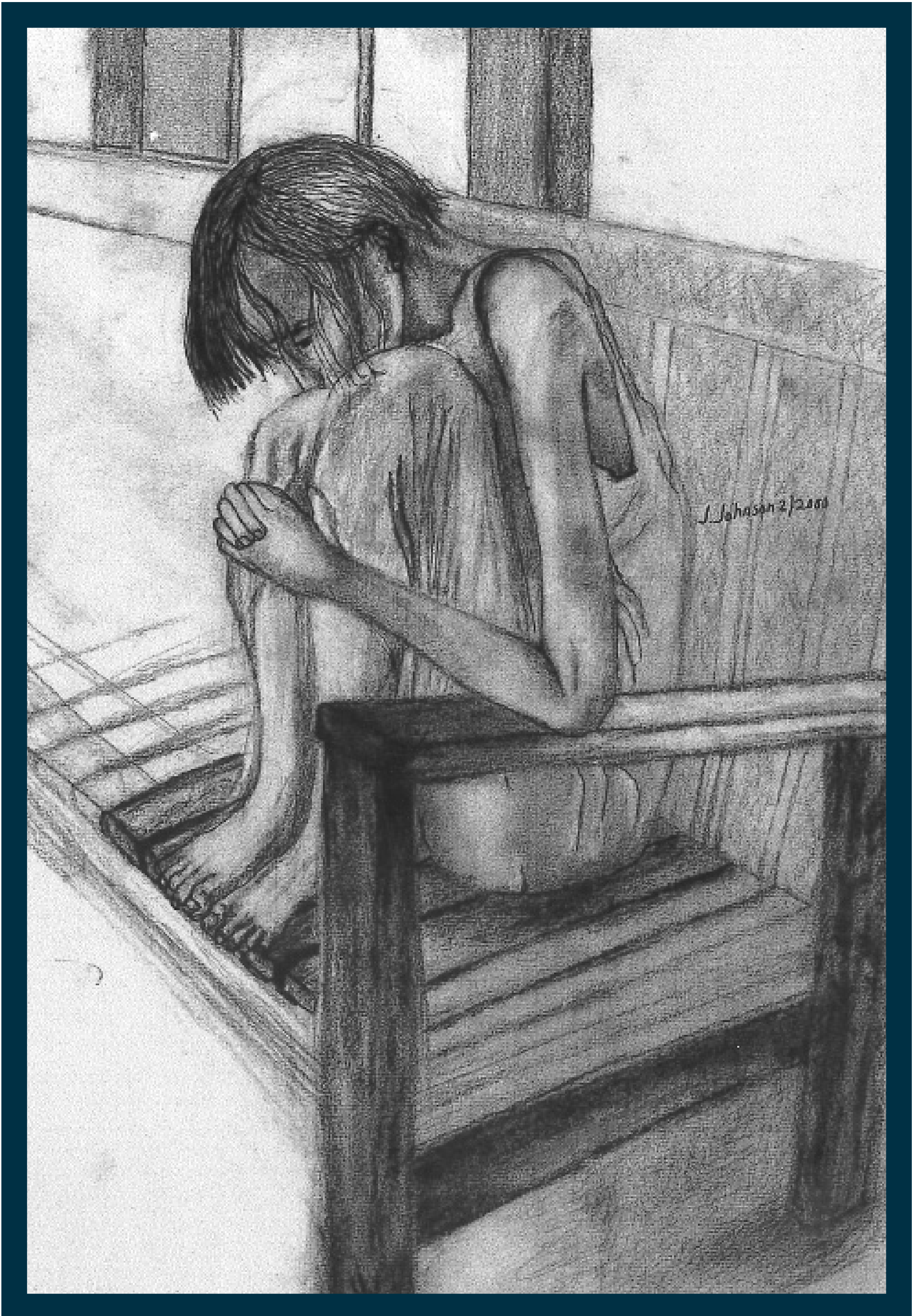
A Personal Journey

From her experiences as an abused child which led to years of psychiatric treatment and medication, to the fulfilment she now finds in her art and poetry, Jean Johnson describes her own personal, ongoing journey of recovery.

Jean, could you talk about your childhood and how you've struggled to define what recovery means for you?

JEAN JOHNSON: As a child I was badly abused to the point where I did not develop cognitively as well as I should have. When I was a young woman I became very depressed and at 23 years of age was put into the hospital and given shock therapy. This absolutely devastated me, I came out of the treatment having no idea of who I was. The shock treatment continued, and it has taken me many years to recover from treatment that was supposed to help me. I was also drugged very heavily when I was ill, to the extent that I was really not aware of a whole lot that was going on around me. It's been a constant struggle to recover. I married, raised two children and worked very hard. A key factor in my recovery process was when I stayed at a Buddhist monastery for a month. I've been a practising Buddhist now for 11 years, and the meditation has helped my recovery process. I also studied at McMaster University, became an artist and presented my work in England. I have also written a great deal of poetry that has been published. My recovery has been very slow, very hard, very painful. I've had seizures. I've had times when I would lock myself in the

"To return renewed with an enriched perspective of the human condition is the major benefit of recovery. To return at peace, with yourself, your experience, your world, and your God, is the major joy of your recovery."
GRANGER, 1994, P. 10



closet and scream from the emotional pain. The only way that I can define recovery is that I have to really believe in myself. I have had to have complete belief in myself even at times when nobody else has believed in me.

In a paper written by Dr. Nora Jacobson on recovery, she wrote that hope was one of the key internal conditions that consumers of mental health services talk about when describing their journey of recovery. The belief you had in yourself, did that give you hope?

JEAN JOHNSON: Yes, believing in myself gave me that hope that I was going to get through what was happening to me. It's so hard to make somebody believe in themselves – you can't really do that but you can encourage people. My belief in myself enabled me to never give up, to keep working as hard as I could. My idea of recovery is not 'I'm okay now I can stop doing what I'm doing, I'm where I want to be'. I don't think anybody, whether they have a mental illness or not, ever reaches a point where they are 'okay'. We are always evolving, always working towards that goal. One tool that I have used in my recovery is writing. I have journaled for about 15 years, journaling my thoughts, my feelings, asking questions and answering the questions. Sometimes writing about my experiences has made them feel more real, it was as if I was re-experiencing them. I've also done a lot of deep meditation, and of course my painting has been really important to me. I paint people, their expressions, and I learn a lot from my work, from the paintings I produce. Also when I have an opening or an exhibition I feel really proud of what I've done and I have an enormous amount of respect for myself.

"Recovery is a process, a way of life, an attitude and a way of approaching the day's challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup and start again... The need is to meet the challenge of the disability and to reestablish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work and love in a community in which one makes a significant contribution."
PATRICIA E. DEEGAN

It's been said that people who have psychiatric disabilities often find that they lose their "selves" inside mental illness. From what you're saying it sounds very much as though you have re-discovered your "self" through your poetry and painting.

JEAN JOHNSON: That's true. I think I lost myself when I had the electroconvulsive therapy and the drugs. The meditation was what helped me to gradually come off of all the drugs I was on after I came back from the monastery. Another point on the journey towards recovery for me was when I confronted one of the people who had abused me so badly and told him I never wanted to see or hear from him again. That was a pivotal point in my recovery, it was like taking the world off my shoulders.

Was that an empowerment issue for you when you confronted them?

JEAN JOHNSON: I would say it was an empowerment issue. I began to take charge of my life. I am still recovering – I am still journaling and painting. I am thinking of working with other people and maybe teaching them art. I also presented my work in England at two mental health conferences a couple of years ago, so I keep very busy. Having a mental illness is such an insidious thing to live through in terms of other people because of the stigma attached to it and because of how other people think of those who have a mental illness. They say and do things to people that they would never think of doing to someone who hasn't suffered with a mental illness. And some people aren't strong enough or they don't believe enough in themselves to stand up to it and say 'I don't deserve that'. I am very careful about what I allow other people to say to me. If somebody is verbally abusing me, calling me a name or something, I

make sure I say something to them because I don't feel I deserve that and I won't take it. Stigma is a terrible thing. I've been in periods of my life where I've had nobody and I've had to be strong.

As you've pointed out, recovery is a continuing journey and although somebody else can't make you recover, they can provide an environment in which it is easier for you to take those steps towards recovery. You've mentioned stigma, but what are some other external conditions that are not helpful to someone who is on this journey?

JEAN JOHNSON: I don't think people need people who don't know what they are talking about telling them what to be and what to do. It's like a child, you don't tell a child how to play with a certain toy, you allow a child to evolve and grow, and that I think is the basis for recovery. Learning about oneself, accepting oneself – how can we do that if someone else is telling us how to live our life? I think in some ways I was fortunate that my family virtually disowned me when I started talking about abuse issues and nobody wanted to hear about it. At times it was devastating not having anyone, but on the other hand it was very empowering because I could make my own decisions about how I was going to recover and what I was going to do. And I had a lot of very good friends in the mental health field who took the place of family.

> *"Having some hope is crucial to recovery; none of us would strive if we believed it a futile effort... I believe that if we confront our illnesses with courage and struggle with our symptoms persistently, we can overcome our handicaps to live independently, learn skills, and contribute to society, the society that has traditionally abandoned us."*
> LEETE, 1989, P. 32

Do you think that things like dignity, trust, respect and love are typically given to people with mental health disorders?

JEAN JOHNSON: No I don't. Ideally it would be wonderful to say yes they are, and I'm not saying that they are never given to people with mental health issues, but in many cases they aren't given. One example of what can happen when people are shown love and respect is a friend of mine who was in university getting his masters degree in science when he was first diagnosed with schizophrenia. He was devastated. He was given shock therapy and he had to move in with his mother, but his mother loved him, looked after him and today he's married and he's fine because he was given a protective place to live. He was respected, given compassion, and I would say he's totally recovered. At one time he had lost everything but now he has everything. He wasn't hospitalized over and over again because he had a safe place to live, decent food to eat, he had health coverage and he had someone showing him some respect.

Do you think there is a difference in the way that people are treated in general now in the mental health field compared to when you were diagnosed and treated?

JEAN JOHNSON: I'm not really involved in the mental health services at all now. I know when I was recovering I was going to the CMHA drop-in centre and it was excellent. We played cards and bingo and sat around and drank coffee and talked about our doctors and our experiences and we helped one another. That was a huge stepping stone for me to know that there were other people who suffered with the same kind of thing.

Dr. William A. Anthony, Executive Director of the Center for Psychiatric Rehabilitation at Boston University says that recovery is "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 illness."

JEAN JOHNSON: That's a beautiful description of what recovery should be for anyone. You know it's interesting, but when I was married my husband

was always saying 'I just want you to be happy and well', but the minute I would start getting well it was like he would pick up a hammer and hit me over the head. People say that they want you to get well but when you begin to start taking steps of showing wellness, that means they have to change how they think of you, and there's a lot of ambiguity in that area. I think they understand you when you are ill but when you start to get well they don't know what to expect anymore. It may be frightening for them. I sometimes say that I have recovered but my family hasn't recovered from my mental illness because if they were around me now they wouldn't know how to react to me.

Have you come to terms with your past?

JEAN JOHNSON: I am still coming to terms with the past. I don't think we can ever say we've accomplished it, we've done it. We are constantly evolving and growing and I have come to terms with what I have been able to so far, but I'm still working on that. For instance when I am painting, and I put a canvas up on the easel, sometimes I can feel the emotion almost as if it is coming from the canvas to me – I learn something from every painting that I do. My life now, probably because of my Buddhist beliefs, my art, my journaling and writing, has a lot of meaning. More meaning maybe than some people who have never had a mental illness. I am able to function at a very good level and deal with anything from the past that comes up. But I do have to live a very structured kind of life. I have to know my limitations and I have to be really diligent about not doing something that could cause me to become really upset or put me into a position where I may not do very well.

Do you have supportive relationships in your life Jean?

JEAN JOHNSON: Yes, I have many good friends who are very supportive. People who know me well know what I've come through, and I really believe that they respect me, especially when I do a presentation. I have a lot of poetry I read, and I show my paintings on an overhead, and it's very fulfilling. I feel that I am doing something worthwhile. I learn from the audience and they learn from me. Sometimes people are brought to tears because the poetry can be very emotional, but it's a very worthwhile experience.

If you were able to have some input into revamping the mental health system so that it became more recovery-oriented what are some of the things you would like to see in place?

JEAN JOHNSON: I think one thing I would emphasize is believing people when someone is reflecting on where they are at in their life, how they are doing. Believing that is exactly who they think they are at that point and respecting what they have to say about themselves and respecting what they need. A worker does not know better than the consumer what they need – it's impossible for them to know. That kind of respect leads to belief in ourself and belief in our ability to move towards recovery.

NOT EVEN THE NIGHT AIR IN SUMMERTIME

Harsh words make me want to hide
inside of bones that reach up
and live in my senses.
They are brittle and barren now.
They carry the scenes of my younger years,
along with the clutter of coloured threads,
that wrap these bones holding them in place.

Sometimes I think I will lose myself
once again inside of these bones,
where I am safe and soundless
and nothing hears me,
not even the night air in summertime.

In the morning I will look out of these bones
and walk barefoot feeling the warmth of the sidewalk
on the palms of my feet
and my bones will rattle like crickets
in the night air in summertime.

JEAN JOHNSON

Shaping a Recovery Philosophy

The Honourable Michael Wilson, Chair, Toronto-Peel Mental Health Implementation Task Force and Vice-Chair, Provincial Mental Health Implementation Task Force Forum, is t President and Chief Executive Officer of Brinson Can. Co. Mr. Wilson has held senior federal cabinet posts wi the Government of Canada in Finance, Industry, Science and Technology and International Trade, and is director of a number of companies, including BP p.l. and Manufacturers Life Insurance Company. He has been active in a number of community organizations in Canada and the United States including the Centr for Addiction and Mental Health and the Canadian Neuroscience Partnership. He is also Senior Chairman the Global Business and Economic Roundtable on Addictions and Mental Health and, in that capacity, has spoken frequently about mental illness in the workplace.

Let me read you a quote from Patricia Deegan from an address she gave at The Sixth Annual Mental Health Services Conference of Australia and New Zealand: "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...to form a community of hope which surrounds people with psychiatric disabilities..." As we move towards a new vision of mental health services grounded in the idea that people can recover, how do we put in place this kind of environment?

MICHAEL WILSON: The recovery process itself starts with the individual. I think it was best put by one of the people who presented to us. He showed a circle, and then another circle within that circle, and said that in the depths of mental illness the bigger circle is the illness and the smaller circle is the individual. The recovery process starts as the individual sees him or herself as the bigger circle and the smaller circle as the illness. We also have to recognize the importance of family, close friends and other social networks as being the immediate supports that will give that individual the confidence, the sense of independence, that can develop the 'community of hope' that Patricia Deegan spoke about in the quote you read to me. Obviously clinical supports, the right medication, support from psychiatrists, social workers and other support groups are important for that individual. Two other very important components are having a home and having a job, or some other occupation that

will give a sense of involvement and association with others. So it's a combination of things – we have to have a receptive and supportive community, and I use the word community in the broadest sense.

Several people I have spoken to have made the point that there isn't just one recovery model because recovery means different things depending on the individual. The Report of the U.S. Surgeon General* also makes this same point, "there is neither a single agreed upon definition nor a single way to measure recovery...". How then are we going to be able to measure whether we are in fact putting in place system standards that will be consistent with this new vision of recovery?

MICHAEL WILSON: You can measure your recovery from a broken leg when the bones have knit and you are able to walk without discomfort and start playing sports again. Mental illness is different. There are some people who will have what you and I would describe as a full recovery. There are others who would have what we could describe as a functional recovery, where they could do a lot of things they did before and not have any real effects from their mental illness but they know that it's there, they know they have to be careful and watch for signs of things returning. And then there will be others who will be continually affected by their illness. I think the importance of the recovery philosophy is to allow people to recover the greatest amount of their capacity to do things that they could before they suffered from their illness; to allow them to achieve independence and a quality of life that they didn't have during their illness. But it will be the individual who will be the judge of whether or not he or she has recovered.

"A recovery vision of service is grounded in the idea that people can recover from mental illness, and that the service delivery system must be constructed based on this belief. In the past, mental health systems were based on the belief that people with severe mental illness did not recover, and that the course of their illness was essentially a deteriorative course, or at best a maintenance course. As systems strive to create new initiatives consistent with this new vision of recovery, new system standards are needed to guide the development of recovery oriented mental health systems."

A Recovery-oriented Service System: Setting Some System Level Standards
WILLIAM A. ANTHONY, PH.D., EXECUTIVE DIRECTOR OF THE CENTER FOR PSYCHIATRIC REHABILITATION AT BOSTON UNIVERSITY.

Do you think this is a difficult concept for people in the larger community to understand? We live in a society that wants to see everything 'fixed'. Can the general public understand that recovery does not necessarily mean perfection, but relates to the goals that each individual has?

MICHAEL WILSON: We may live in a world where we want everything to be perfect but we also recognize that we live in a world where there are very few things that *are* perfect. Perfection is not achievable. My wife just had a knee replacement. She's walking well, we played golf for the first time the other day, and she's very happy with the operation. But are we going to go skiing this winter? No! There is a limitation. She feels that she's had a good recovery. She feels a lot better and doesn't have some of the pain she had before, but it's certainly not perfect. I think we can understand that concept as it relates to mental illness. And in fact, that's what makes the recovery philosophy so important in breaking down old attitudes about mental illness – everyone can relate to having recovered or being in recovery from something.

At what stage is the Task Force at in its deliberations? Who has it met with and what has been discussed to date?

MICHAEL WILSON: Well we're at a fairly late stage. We started our work in January 2001 and have now finished the first phase of our work which is looking at the various supports and services that are in the mental health system. We had

consultations in the spring of this year [2002] regarding the ideas we have to improve the delivery of those services and supports. We have looked at systemwide issues: how do we manage the new system? What sort of elements do we have to have in the management of the system? We have looked at some broad system-wide issues such as human resources issues, information technology, training of individuals, public education issues, as well as issues relating to research and best practices. A second phase of our consultations is just being completed, and we are studying the results of all of the consultations that have taken place. We plan to present our final report to the Minister in early December.

So consumers and service providers of all kinds have been involved in these consultations?

MICHAEL WILSON: In Toronto and Peel Region alone there have been thousands of people involved either directly or indirectly in these consultations, so you can multiply that by another factor to get the numbers in the rest of Ontario. We've had people on the Task Force, people on the sub-committees, people on working groups that were helping sub-committees. We've had presentations from consumer groups, from providers, from family groups, from housing providers and from hospitals. We've had consultations which have involved many other people representing various elements of the mental health system. In some cases, in our second phase of consultations, we had representations from a number of organizations, so that while we maybe only had one or two people physically present at the consultation, they represented a range of other people who are involved in the mental health system. I have also done some visiting with various delivery level organizations, housing groups, and crisis groups and we have people on the Task Force whose day job is in these types of organizations – family doctors, psychiatrists, people from the Centre for Addiction and Mental Health (CAMH), housing, drop-in centres, consumer peer support groups – a whole range of people.

"The concept of recovery is rooted in the simple yet profound realization that people who have been diagnosed with mental illness are human beings. Like a pebble tossed into the centre of a still pool, this simple fact radiates in ever larger ripples until every corner of academic and applied mental health science and clinical practice are affected. Those of us who have been diagnosed are not objects to be acted upon. We are fully human subjects who can act and in acting, change our situation. We are human beings and we can speak for ourselves. We have a voice and can learn to use it. We have the right to be heard and listened to. We can become self-determining. We can take a stand toward what is distressing to us and need not be passive victims of an illness. We can become experts in our own journey of recovery."

PATRICIA E. DEEGAN, PH.D.
Recovery as a Journey of the Heart
First published in the Psychiatric Rehabilitation Journal, 1996 Vol. 19 No. 3

Dr. William Anthony, Executive Director of the Center for Psychiatric Rehabilitation at Boston University lists nine essential services that should be present in a recovery-oriented system – treatment, crisis intervention, case management, rehabilitation, enrichment, rights protection, basic support, self-help and wellness/prevention. Has the Task Force come up with a list of essential services that they believe are necessary?

MICHAEL WILSON: We are in the final stages of making up our report, and we have addressed some of those points. However, you have to recognize that this is not a clinical document. We are not telling doctors how they should treat patients. We are looking at the mental health system from the standpoint of the consumer: how do they access the system? How do they find a doctor? How do they get to the hospital? How do they get treatment in the emergency room? How do they get a referral from the hospital to appropriate housing supports? That's the sort of work we are

doing as opposed to saying, 'here are a number of things that have to be done in the clinical support of a mental health consumer'.

You mentioned that the Task Force has been discussing how to improve delivery of services. How will that be done?

MICHAEL WILSON: You are asking a huge question. This is not going to be a short report. We have recommendations on how you access the system, recommendations on how those front line services and supports should interact with the rest of the system. When someone receives support in a crisis situation where do they go from that point? We are recommending ways to link that individual at a crisis point with the next stage along the way: how to link with peer support, family support groups, consumer organizations, consumer run businesses, housing. We want to be able to match people to the degree of support that they need. We have done some work to show that at present there are people who receive more treatment than they need and others who receive less than they need. Sometimes a lot less. So we are trying to get systems in place that will provide better matching between the needs of consumers and what is available.

"The Task Force is committed to the recovery philosophy, with recovery being defined by the individual. Recovery is something that is worked towards in collaboration with, and informed by, the expertise and support of the consumer, family members, peers, mental health support workers and medical professionals."

HON. MICHAEL WILSON
Chair, Toronto-Peel Mental Health Implementation Task Force, Vice-Chair, Provincial Mental Health Implementation Task Force Forum

Let me end by reading you this quote, again from Nora Jacobson, from a paper entitled Recovery as Policy in Mental Health Services: "with vision statements in hand some states simply rename their existing programs. The actual services offered remain the same...this renaming process demonstrates a lack of understanding of recovery, in particular a failure to acknowledge the necessity for a fundamental shift towards sharing both power and responsibility." Are you confident that we will end up with a true shift in the way mental health services are structured and not just a cosmetic 'name change'?

MICHAEL WILSON: Our intention was to adopt the recovery philosophy as the touchstone against which to develop and test our recommendations. This recovery philosophy is a driving, fundamental value, that we believe should be followed as we develop these new approaches to providing care and support. There will be changes proposed in our system. There will be changes that draw on elements of the recovery philosophy because that is the central guideline in what we are doing. If we can make the changes that allow the structures to support the recovery philosophy then I think we are doing a lot to move the system into that way of thinking. The answer to your question is broader than the work of the Task Force, but you will see that right up front in the report is our statement of dedication to the recovery philosophy and we have tried to do things and make recommendations in the Task Force report that will support that.

The final report of the Mental Health Implementation Task Force will be presented to the Minister in December.

**Mental Health: A Report of the Surgeon General can be seen in its entirety at www.surgeongeneral.gov/Library/Mental Health/chapter 2/sec10.html*

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BIBLIOGRAPHY AVAILABLE

An extensive bibliography of Recovery Resources prepared by Barbara Adams, Senior Analyst and Teresa Croscup, Information Officer, Canadian Mental Health Association, Ontario Division can be found on the CMHA, Ontario Division website www.ontario.cmha.ca under 'Policy Documents'.

MENTAL HEALTH WORKS

- The World Health Organization has predicted that by the year 2020 depression will be second only to heart disease as the leading contributor to the global burden of disease.
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