

What is this thing called recovery?

A look at Five Stages in the Recovery Process

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Part 1: The Shift to recovery

I want to talk about two shifts that have taken place –

First, we will look at the shift from stabilization and maintenance to self-help and recovery; and then, the shift from self-help and recovery to system transformation.

This shift is held in the following image.

	1980	2003
Belief: People cannot recover	People can recover	System needs to support recovery
Task: Stabilize and Maintain	Introduce recovery programs	Systematize recovery

Up until around 1980, the beliefs that dominated the mental health system were...

(1) ...people diagnosed with a severe mental illness would not recover, and more than likely the illness would get progressively worse;

(2) ...the most you could expect in terms of treatment was to get people stabilized and then maintain them as best you could in ‘supervised’ environments in which they would not be able to harm themselves or others and would not be causing too many problems; and

(3) ...this stabilization and maintenance usually involved high doses of medication, long stays in secure institutions and/or years in ‘day treatment programs’ designed to entertain with TV, table games, recreation, trips, outings and other ‘low stress’ activities.

It is important that we understand the mindset and beliefs of what I call “the old

system”, because these beliefs can still be found in many agencies and organizations today. They are a major force working against recovery.

Around 1980 this began to change. At this time there was a shift from stabilization and maintenance to what was called ‘self-help and recovery.’ Four things played key roles in enabling this change.

First, consumers like Judi Chamberlain, Patricia Deegan and others began to write and talk about their own lives. Consumers were saying to providers in a variety of ways that “our lived experience with mental illness does not agree with your learned experience about mental illness. “We are capable of moving on with our lives – often in spite of the system.”

Second, researchers like Dr. Courtney Harding were designing and implementing longitudinal research projects that were challenging some of the old myths about schizophrenia. Their research showed that people who have been very disabled by a severe mental illness could live a meaningful and productive life in the community when given the right skills, resources and supports.

Third, the philosophy of psychosocial rehabilitation began to emerge. This philosophy was based on the belief that people diagnosed with a mental illness can live in the community when given the opportunity to develop skills, resources and supports in relation to working, living, learning and socializing.

Fourth, there was an improvement in medications which better controlled symptoms and had less harsh side-effects.

By the early 1990's, the concept of recovery had gained a foothold in many programs across the country. Dr. William Anthony, Boston University Center for Psychiatric Services, calls the 90's the 'Decade of Recovery'. Individual consumers and staff were beginning to believe in the possibility of recovery, but as they began to creatively bring the concept of recovery into a variety of environments and program settings, they continued to run up against the constraints of the system. The system was not ready to embrace concepts like 'strength-based', 'client-driven', 'staff-client partnerships' as the major focus of treatment. It was as if they were trying to put 'new wines into old wineskins.'

In 2003 there was another shift. I am going to use the **President's New Freedom Commission Report on Mental Health** to symbolize the shift that took place early in this century.

While the 2003 report promotes the concept of recovery in its vision statement, it goes on to state that the mental health system is in disarray and needs to be transformed. It adds that the major focus of the current mental health system is not recovery. The system, according to this report, is currently oriented to meet the requirements of the bureaucracy (system) and NOT the consumer. It focuses mainly on increasing the consumer's ability to 'manage symptoms' and NOT on 'managing life's challenges'. The report goes on to state that if recovery is to take hold, staff alone cannot do the job. The system itself will have to become more supportive of recovery.

We cannot begin to develop a recovery-oriented system or a recovery culture if we cannot agree on both the possibility and process of recovery.

Knowing that recovery is a unique journey, are there common experiences within that

unique journey? Appalachian Consulting Group thinks that there are at least five common experiences. We call these five common experiences 'Five Stages in the Recovery Process.' But before we get into the stages, let's look at what we mean by the word 'recovery.'

Part 2: What is meant by the word recovery in relation to mental health?

The Oxford Mini Dictionary defines 'recover' as "to regain possession or use or control of..."

Keep that definition in mind as we proceed.

Recovery from mental illness has often been linked to words like – regain, restore, rebuild, etc.

The following is an example of this kind of definition.

"Recovery is a process of restoring a meaningful sense of belonging to one's community and a positive sense of identity apart from *one's condition* (italics added) while rebuilding a life despite or within the limitations imposed by that condition." (Davidson, et al 'Creating a Recovery Oriented System of Behavioral Health Care: Moving from Concept to Reality, 2005)

Dr. William Anthony states' "Recovery is not the absence of symptoms, but the development of *new* (italics added) meaning and purpose as one grows beyond the catastrophic effects of mental illness."

These statements seem to assume that at one time a person had a life – a life with hopes, dreams, roles, responsibilities, and expectations. This life was lived in the larger community. It was expanding and future oriented. A person's self-image and self-story was pretty much intact. He was aware of his abilities, his potential for growth

and had some sense of where he wanted to go and how he was going to get there.

Then something happened. That life was interrupted by the onset of what we call a 'mental illness.' Hopes, dreams, roles, responsibilities and expectations in the larger community were shattered. On the other side of that catastrophic shattering, life in the larger community was often lost and replaced by 'life in the mental health system'. One's hopes, dreams, roles, responsibilities and expectations were reduced to the small, restrictive world of the mental health system.

Recovery, then, becomes the process of moving as much of one's life as possible back into the larger community. It involves re-building one's self-image and self-story in relation to one's ability and one's potential for growth. It involves recreating roles and responsibilities in the larger community. It involves reframing one's hopes and dreams so that they are not just about illness and life in the mental health system, but about wellness and life in the larger community.

Why do many people find this to be so difficult? What works against this happening? We will come back to these questions later. For now let's continue to explore how we are using the word 'recover' in the peer specialist training.

The traditional use of the word 'recover' in mental health implies that something needs to be restored, regained or recovered. It assumes that 1) the person has been separated from the larger community in which most people live and function; 2) the person has been separated from his hopes, dreams, roles, responsibilities and expectations as a member of that larger community; 3) the person's identity has been reduced to seeing himself as his illness and its disabilities; and 4) the person does not have a life outside of his illness, the treatment he is receiving for this illness

and the activities he is involved in within the mental health system.

The President's New Freedom Commission states "We envision a time when everyone diagnosed with a mental illness will recover - *or be able to recover, regain, or rebuild a life in the larger community.* (Italics added.)

All of this said, there are people who have been diagnosed with a mental illness who have not experienced this as a catastrophic shattering of their world hopes and dreams. They have not 1) been isolated from society in general and placed within a mental health system; 2) come to see themselves as the illness and its disabilities; (3) confined their hopes, dreams, roles, responsibilities and expectations to a life within the mental health system; and 4) restricted their lives to activities in the mental health system. Therefore, they do not need to 'recover' a life in the larger community in the traditional sense. If this is true, how does the traditional way of looking at recovery relate to them? I am not sure that it does. For them their mental illness has not been a major interruption in their lives.

Yet, for many, if not most, people currently receiving services from the public mental health system, this has been a 'catastrophic' event. They have experienced the kind of interruption, separation and disconnect implied in the traditional definition. This being true, it seems that we could say that this definition does not directly apply to 'recovery' from mental illness in general, but to recovery from the way that a person diagnosed with mental illness has been or is being treated by both the system and society.

Maybe a more appropriate vision could be held in the statement –
"We envision a time when everyone diagnosed with a mental illness will not experience that diagnosis as a catastrophic event in his life that

- 1) isolates him from the larger society by placing him in a mental health system,
- 2) causes him to see himself as the illness and its disabilities;
- 3) reduces his hopes, dreams, roles, responsibilities and expectations to those of a mental patient; and
- 4) creates a belief that he does not have a life outside of his activities within the mental health system.

Rather than approaching mental illness as a condition that either must be cured or for which there is no hope, mental illness needs to be seen as a long-term illness or condition that a person can learn how to manage and live with over time; and in doing so will require less intensive, less frequent, less costly and less time consuming interventions. The role of the mental health service system then becomes helping the person “identify and build upon his assets, strengths, and areas of health and competence to support him in managing his condition while (re) gaining a meaningful, constructive sense of membership in the community.” (Davidson, et al)

People need to have immediate access to services and supports that they need at any given time, while being encouraged to find as many supports as possible in the larger community outside of the mental health system. From the onset, the focus needs to be on “What would you like to be doing that you are currently unable to do, or are having difficulty doing?”, and “How are the symptoms of the illness working against you doing that?” From the onset, the focus is not limited to treating the illness (with the often implied messages that life is somehow over), but also includes helping a person stay focused on what she would like to do with her life. This gives motivation to deal with the symptoms that are making it difficult, if not impossible, for her to do that. The focus no longer is limited to “What is it going to take for you to be able to manage your illness?” But to “What is it going to take

for you to live more independently in the community?” When you change that question, you change everything, because you change the focus from how are you going to deal with your weakness to how are you going to use your strengths.

When we talk about system transformation is it helpful to talk about a recovery-oriented system? Is this not building the new system on the assumption that the onset of mental illness means that a person will lose something – if not everything - and the system needs to be oriented to helping him get that ‘something’- or ‘everything’ restored?

Or do we build the new system on the assumption that a person diagnosed with a mental illness can learn to manage his illness early on while continuing to create the kind of life he wants without ever having to be isolated from the larger community for an extended period of time, without ever seeing himself as the illness and its disabilities; without ever reducing or giving up his hopes and dreams; and without ever having to create a life for himself within the reduced framework of the ‘mental illness’ community?

The task today is to transform the system. What that transformed system needs to look like or what are the basic beliefs that will form the foundation of that system is another discussion. This will require creating a new vision of how mental illness is perceived and how mental health services are delivered. But until that happens, we will continue to have many people whose lives have been catastrophically shattered by the onset of a ‘mental illness’ and the way the system and society has related to them.

We need to find ways to continue the discussion on system transformation. We need to find ways to involve people at all levels of the system in that discussion. But while having that discussion, we need to

stay focused on the plight of thousands that have been disabled, isolated, and demoralized by the old system.

The system itself needs to get clarity and consensus on what the potential, the possibility and the process of recovery looks like for the person who has been isolated from the larger community and placed within a mental health system; the person whose hopes, dreams, roles, responsibilities and expectations are limited by his life as a member of the mental health system; the person who has come to see himself as the illness and its disabilities; and the person who does not have a life outside of his activities within the mental health system.

The training for peer specialists does not focus on system transformation. That does not mean that peers being hired in the system as service providers will not have a transforming affect on the system. It simply means that is not a major focus. The major focus is on the individual recovery process or the recovery journey of the person who has had his life impacted by both the mental illness and the beliefs of the old system and society about mental illness. In coming to some agreement about the potential, the possibility and the process of recovery for this person, I believe that we will move our discussion about system transformation to a deeper level.

It is in light of this that I think the concept of “Five Stages in the Recovery Process” provides a helpful framework for dialogue.

Part 3: A Definition of Recovery and Hope

In order to set the stage for presenting the ‘Five Stages in the Recovery Process’ let’s first talk about how the word ‘recovery’ is used in the peer specialist training. Most would agree that there is no commonly accepted definition of recovery. So the question is what do I, as the major designer

of the peer specialist training curriculum, mean by ‘recovery’ when I am talking about the recovery process? My favorite definition is an adaptation of a definition that comes from a brochure written by the Mid-Hudson Forensic Psychiatric Center in Middletown, NY.

Recovery is the process of gaining control over one’s life – and the direction that one wants that life to go – on the other side of a psychiatric diagnosis and all of the losses usually associated with that diagnosis.

There are four things I like about that definition. First, it mentions ‘gaining control over...’ as oppose to being controlled by... Second, it focuses on ‘the direction that one wants one’s life to go.’ Setting a goal, or getting in touch with what one wants one’s life to be like, is the heart of the recovery process. Third, it talks about the ‘losses usually associated with a psychiatric diagnosis.’ There is nothing a person can lose that can’t be lost as the result of a psychiatric diagnosis. The mental health system does not do a good job in helping people work through or grieve their losses. Fourth, it does not equate recovery with the absence of symptoms or with ‘cure.’ It is not that symptoms are not important. They are, and they can be very disabling. But recovery for most people means the symptoms are under control enough that they are not preventing the person from working to create the life that she wants.

When we think about recovery, we almost immediately think of the concept of hope. Hope is often seen as the foundation or cornerstone of the recovery process. The following definition comes from the same brochure.

Hope is the belief that one has both the ability and the opportunity to participate in the recovery process.

Hope is not ‘I hope it doesn’t rain today.’ I have no involvement in whether or not it rains today. Hope is not ‘the light at the end of the tunnel.’ Hope is a belief. It is the belief that there is light at the end of the tunnel even when I do not see that light. To hold the hope for another is to believe in that person’s ability when she is unable to believe in her own ability.

The staff of Appalachian Consulting Group has been working to articulate major aspects of the recovery journey or recovery process. We have been working to create a common understanding in order to develop a training curriculum in which all of the training sessions speak to and support that process in a constructive manner. We are not interested in debating the cause of what is called ‘mental illness’ – genetics, trauma, fate, etc. – but in the impact a mental illness and/or a diagnosis has on an individual and the beliefs individuals create about themselves in the midst of and on the other side of that experience.

Knowing that recovery is a unique journey, our basic question was – “Are there common experiences within that unique journey?” We think there are at least five common experiences.

Part 4: Five Stages in the Recovery Process©

We have developed what we call “Five Stages in the Recovery Process©” to speak about those common experiences. We call these experiences ‘stages’. While there is a lot of ‘grey’ in the stages, each stage does seem to have its own unique characteristics. Because Patricia Deegan’s work has been very helpful, I have included a copy of her paper that we use in the peer specialist training in the Appendix. In that paper she speaks of five phases – shock and denial, despair, hope and courage, the will to act and responsible action. We use the term ‘stages’ instead of ‘phases’ and have

renamed them **Impact of Illness, Life is Limited, Change is Possible, Commitment to Change and Actions for Change.**

In order to understand the concept of ‘Five Stages in the Recovery Process©’, one first needs to understand what works against a person with a mental illness moving on with her life? Or what it is about a mental illness that makes it difficult for people to function in the traditional roles and responsibilities of society? This takes us back to our earlier question “Why is it difficult to re-create a life in the larger community when a person’s hopes, dreams, roles, responsibilities, and expectations have been reduced to a life within the mental health system?”

What is the disabling power of a mental illness? (See illustration below.)



The symptoms of the illness can be very disabling. It is very difficult to function when one is in a psychotic state and not in touch with reality or when one is delusional, depressed or manic. The side-effects of many medications can also be disabling. It is difficult to function when one cannot concentrate, when one feels drugged, when one has extreme weight gain, when one is sexually dysfunctional, etc.

While people who do not have a diagnosis will almost always mention the symptoms as the most disabling aspect of a mental illness, this is not the first thing mentioned most often by people who have lived with a

mental illness for years. If you ask people with a psychiatric diagnosis what is disabling or disempowering about the diagnosis, they will almost always talk about stigma first. The way others see you, relate to you, talk about you, what they expect from you – or do not expect from you – is often listed as the most disempowering or disabling aspect of that illness.

Another interesting discovery is that if you ask people diagnosed with a mental illness to make two lists – one list of what the symptoms of the illness keep them from doing and a second list of what their fears, low self-esteem and negative self-talk keep them from doing - the second list is almost always longer. Many people are often more disabled by what they believe about themselves because they have a mental illness than by the illness itself.

So in the training when we talk about the disabling power of a mental illness you need to remember that we are talking about the symptoms and the side effects of medications, the impact of stigma and the impact of both symptoms and stigma on one's self-image – and most often it is an inter-play of all three.

Let's go back to the concept of Five Stages in the Recovery Process©. They are not really five 'stages'. What we are talking about is...

“Five ways that people with a mental illness relate to the disabling power of that illness at various times in their lives”.

But that is not a very catchy phrase.

It is not so easy to remember, so we went back to calling them “Five Stages in the Recovery Process©”. But in order to hold the insight that they are really *“Five ways that people with a mental illness relate to the disabling power of that illness at various times in their lives”* we use the phrase...

“There are times when a person...”

There are times when a person is relating to the disabling power of a mental illness in a particular way. I want to give you a quick overview of those stages, and then we will take time to go into depth with each stage.

Impact of the Illness – There are times when the person is overwhelmed by the disabling power of the illness. She is struggling with the symptoms of the illness, the behavior brought on by the symptoms and the ramifications of this behavior and finds it difficult to function.

Life is Limited – There are times when the person has given in to the disabling power of the illness. He has bought into all of the negative beliefs about 'being mentally ill' and all of the negative implications regarding its disabling power. In giving in he has lost all hope for a better life

Change is Possible – There are times when the person is questioning the disabling power of the illness. She senses that she may be able to do more than she has believed she could do.

Commitment to Change – There are times when the person is challenging the disabling power of the illness. He decides to move out of his comfort zone and begins to make small changes.

Actions for Change – There are times when the person is moving beyond the disabling power of the illness. She begins to see the direction that she wants her life to go and starts taking major steps to move in that direction, often finding a life outside of the mental health system.

At various times in the recovery process, there seems to be some key pivotal points where a person can go one way or the other. One way is moving on with what one wants one's life to be. The other is getting stuck or side-tracked and not having the life

that one wants. These are times when internal and external pressures often come together to side-track or block the journey. In order to understand these crucial points, or dangers, one needs to understand what is going on with the person. Where is this person in the recovery journey?

We will look at the dangers as we look at the stages in more depth. Now let's go back and try to get a feel for what is happening at each stage. I don't want you to think of these stages as 'steps' - 1, 2, 3, 4, and 5. For some there is a sense of movement from one stage to another. For others, they may experience all of these stages in various ways in a single day. For others, they may jump over, back and forth, etc. Remember that they are really the way a person is relating to the disabling power of a mental illness at various times in his or her life. It is possible to be in different stages in different parts of your life. It may be my relationships are in the "life is limited" stage while my employment is in the "actions for change" stage.

Remember that the stages are really ways that people with a mental illness are relating to the disabling power of that illness at various times in their lives". In order to hold this insight, we use the phrase...

...there are times when...

There are times when a person...

...is overwhelmed by the disabling power of the illness. Usually at this stage she is overwhelmed by the symptoms of the illness, the behavior brought on by the symptoms and the impact that both of these are having on her life. The illness is the central focus of her life, and the impact of the illness is the dominant experience in her life. She may be so depressed that she cannot get out of bed. She may be so manic that she is not in control. She may have behaved in such a way that she has cut herself off from many of her former

significant supportive relationships. Or the symptoms and behavior may be under control, but she is so overmedicated that she cannot function. People may be overwhelmed by stigma or how their identity is being redefined or by what has happened to their self-image. But what I am talking about here is being so overwhelmed that one cannot function the way society expects people to function. Usually this is when people are so overwhelmed that they cannot function effectively, the symptoms and related behavior are not under control or the person is over-medicated.

While most people will talk about being overwhelmed by the catastrophic impact of the onset of the illness, the experience is not the same for everyone. Some people may never remember not being 'sick'. They may never remember 'having a life'. Or getting a diagnosis may have come to them as good news. "There is something wrong with me that has a name. Other people have experienced what I am experiencing. I am not alone. Thank God there is treatment for what I have been going through." Therefore, all of the five stages as described in the training may not speak to everyone.

But many, if not most, people experience the onset of symptoms, the resulting behavior and the loss often incurred as a 'catastrophic shattering of their world, hopes and dreams' to use Patricia Deegan's words. People use a variety of words to describe this time in their lives – confusion, shame, loss, shattered, denial, bizarre, not in control, looking for answers. As consumers have talked about this time, there are a number of common themes. Some experience this as a time of 'living two lives.' At work they are 'functioning' or 'going through the steps of living'. But experience no joy, meaning or fulfillment. No life outside of work. They go home and crash. They spend a lot of time alone, in bed. They have no energy. They know that something is wrong, but will not or are not

able to seek help. They try to hide what is going on from others. For some this 'living two lives' goes on for years.

For others their life becomes chaotic, and they often talk about feeling that they are not in control. They don't understand what is happening and often turn to drugs and alcohol for some relief. They experience a lot of loss. They burn a lot of bridges. There is a lot of denial that anything is wrong. Some talk about feeling that they had gone someplace from which they couldn't come back. This is often a time of confusion, anger, fear, and unusual or unhelpful behavior. People's behavior gets them in trouble with the law and results in a lot of loss and rejection. With so much going on, they are often overwhelmed to the point that they cannot function in the way that society expects a person to function.

Remember Patricia Deegan talks about this experience as a "shattering of one's world, hopes and dreams." A visual image for this stage is a precious vase being shattered. If you think of the vase as a person's life, that person is left with two questions - Will I ever be able to put my life back together again? And if I am, will it be worth anything?



While the stages are not steps, there do seem to be dangers at each stage that often work against the person moving on or cause the person to become 'stuck' in a particular stage – or get side-tracked from their journey. There seem to be some key pivotal points where a person can go one way or the other. One way is moving on with what one wants one's life to be. The other is

getting stuck or side-tracked and not having the life that one wants. I call these pivotal points 'dangers'. At each of these stages there is a question that a person must answer. Internally there are pressures to answer the question in a negative way. Externally there are pressures to answer the question in a negative way. When the internal and external pressures come together in a supportive way it often causes the person to get stuck or side-tracked on the journey.

The danger at this stage is held in what I call the **Question of Identity**. How am I going to define who I am and what I can do on the other side of this experience? The **danger** is that the person begins to redefine herself in mental illness terminology which automatically limits her sense of future possibilities, causing her to give up or reduce her hopes, dreams and expectations.

Because of the person's inability to function as society expects a person to function and because of all of the losses and disruption that often is a part of the onset of a mental illness, or of a major relapse, there is much going on that would cause a person to redefine herself in this way. There may be shame and embarrassment for not being who that person and others thought she should be. There may be a sense of hopelessness in that she will never be able to do what she and others thought she could do.

Externally, the system and other people may get caught up in reinforcing these feelings. "I understand that you want to go back to college. But you know this will be a lot of stress. Stress is not good for a person with a mental illness. It often causes them to become symptomatic and relapse and have to be hospitalized. Then there is the stigma. What if people find out you have a mental illness? That can cause stress, also. Etc., etc.

Let me share with you a story that illustrates this. A 17 year, junior in high school was having difficulties. His family, thinking it was typical teenage problems, took him to a family counselor. After a few sessions, the counselor said that she sensed there was more going on than she was qualified to deal with and suggested the parents take the youth to see a psychiatrist. After meeting with the youth, the psychiatrist said, “You have all the signs of major depression.”

What was the next thing you think she said to this 17 year old high school junior? She said, “A lot of people are diagnosed with depression and go on to lead a very meaningful and productive life. I don’t want you to think that this will in any way keep you from doing whatever you want to do.” Then the youth said, “I have always wanted to go to college...” The psychiatrist interrupted him and said, “You are not hearing what I said. A lot of people are diagnosed with depression...” and she went on to repeat what she had earlier said. It is like she was saying, “You still are - and can to continue to be – the person you have been. I am not going to let you create a new identity around your diagnosis.” She was not going to let him live out of an “I am disabled” story. She was determined to help him keep his old identity of a 17 year old with dreams and aspirations.

Because of the power of a doctor’s diagnosis, the danger of redefining oneself is often very strong in the early stages of diagnosis and treatment, but it is not limited to this time. A person may have been doing well for years, and for some reason – crisis in this life, medication stops working, etc. – she begins to struggle deeply with her identity. “I thought I had this licked. What’s going on? Am I ever going to be able to get stable and stay stable?” The danger is always there, especially when the actual symptoms of the illness are disrupting a person’s life whether in the early onset of

the illness or in the midst of what we call a relapse.

Sadly, a psychiatric diagnosis, like many disability diagnoses, may be used to define a person’s value and potential. Low expectations and a dismal future are often the predicted norm. When a person sees everything about herself as ‘sick’ – or broken – there is no well self to do the recovery work. The recovery work is always done by the well self.

The role of services at this point is to decrease the emotional distress by reducing the symptoms and to communicate that there is life after diagnosis.

Then there are times when a person...

...has given in to the disabling power of the illness. Two things often happen at this time. There are major changes in the way that the person sees himself. There are major changes in the way others see and relate to the person. He often begins to experience a sense of hopelessness, helplessness, uselessness, being frightened, ashamed, and self-pity. The ‘disability’ takes on a life of its own unrelated to the symptoms. A person feels an ‘in-ability’ to do various things even though he is not ‘symptomatic’. Despair about one’s present life and one’s future can often have a more devastating impact than the illness itself. Patricia Deegan says, “When one lives without hope, the willingness to do is paralyzed as well.”

I met a woman at a mental health conference who said, “For 37 years I knew my label (diagnosis), but I didn’t know me. For 37 years I was afraid that if I gave up my label, I would not know who I was.”

What does it mean to have given in to the disabling power of the diagnosis? In this stage you believe that you are the diagnosis. The diagnosis has taken over your life and has become the way you define yourself.

The diagnosis has become your identity. All of reality is viewed through the lens of the diagnosis and often negative prognosis about the illness, and you see no possibility of having a different life.

If you believe that there is nothing you can do that is going to make your life the way you want it to be, what do you do? You do nothing. And in doing nothing, you turn your life over to some one or some thing that you hope will make a difference. Many people who have given up on their own ability to make a difference in their lives turn their lives over to the mental health system. Often the system encourages and supports this.

What does that look like? If you ask a person in this stage to tell you something about herself, she will usually tell you her diagnosis, or what program she goes to or how long she has been out of the hospital or something else about her mental illness or her life in the mental health system. The diagnosis and the system have recreated her identity. This is because the system has become her life. She has no life outside of the system. She goes to program. She takes her medications. She sees her doctor. She usually does what she is told to do by the system. If she needs anything, she expects the system to get it for her. If she needs to go shopping, she expects the system to take her shopping. If she wants to go bowling, she expects the system to take her bowling. She does not have a life outside of the system. This is because at some deep level she has been told – been convinced – has come to believe - that because she is mentally ill, she is not able to, nor should she be expected to, do anything for herself.

This stage, 'given in to...' is in some way about the person who, consciously or unconsciously, has reduced his life's major role to the role of being the mental patient. He has bought into the belief that because

he has a diagnosis, his life is limited in ways that may not necessarily be the result of the symptoms of the illness. In this stage, the person may not like his life, but he believes that it is the only life he has. He does not see any possibility that he can do anything that will make his future any different from the present. There is oftentimes a deep sense of resignation, if not despair.

In order to recover, one has to change the way he thinks and acts. Change happens when one is aware that he is dissatisfied with his life the way it is. None of us change if we are not dissatisfied. You can force me to change, but I am talking about self-initiated and supported, positive change. But there has to be more than the awareness of dissatisfaction if one is going to change. There has to be a sense of possibility. There is something that I can do that will possibly make a difference.

There is a great statement in SAMHSA's "Recovery: The 10 Components". "Recovery begins with the initial stage of awareness in which a person recognizes that positive change is possible." Without a sense of possibility, dissatisfaction leads to despair or resignation, and, the greater the dissatisfaction the greater the despair. No one likes to live in despair. I can decide to lessen the feeling of despair by lessening my expectations. I can convince myself that my current situation isn't so bad. "I shouldn't be so dissatisfied. Maybe I am expecting too much. After all, I do have some friends in the day program. They provide me with a good meal everyday. I have my benefits. The program does take me on trips. Occasionally we have parties. Sure my life is limited, but it does have its good points. Really, it is not such a bad life *for a mentally ill person.*"

The person reduces his expectations and blames it on his mental illness. Thus by reducing his expectations, he reduces his dissatisfaction. Then he is able to replace

his despair with resignation. We would all rather live in resignation than despair. Staff can also fall into the trap of supporting this kind of story.

A visual image for this stage is a person sitting in a lazy-boy chair in front of a TV with a cigarette in one hand and the remote in the other. He is gazing at the TV. There is nothing on the TV but static. There is a sense of giving up or giving into a life without hope of anything ever being any different. "This is my life. I don't like it, but it is the only life I have. Just accept it"



At this stage the person gives up or **gives into** the belief that his **life is limited** in ways that may not necessarily be true and lives for years in the mental health system without any possibility for having a different life. The danger at this stage is held in the **Question of Possibility**. How will I relate to possibilities when I have redefined myself as 'mentally ill'?

Again, there is much going on at this stage that may cause a person to not see any possibility. Patricia Deegan states in her attached article, "We both gave up. Giving up was a solution for us. It numbed the pain of our despair. We stopped asking "how and why will I go on?" When one has 'numbed the pain of his despair' by resigning himself to his situation, he does not want to risk that pain reappearing. There is a statement in Allen Wheelis book, "How People Change", that seems to hold what is going on at this stage. "Nothing guarantees our freedom (to change). Deny it often enough, and one day it will be gone; and we will never know why."

At some level I believe the person has decided to not be hopeful. He has resigned himself to his current situation or condition and, in doing so, has moved from despair to resignation. It is as if at some deep level he refuses to see any possibility, because possibility creates hope. Hope demands action. And action involves risk. And risk involves the possibility of failure. The **danger** is that the person will become so comfortable that he will be unable to see the possibility of moving out of that comfort zone. He will refuse to acknowledge that there is anything he can do that will make a difference in his life. Why act if you truly believe that nothing you could possibly do could ever create the kind of life that you want.

Everything the system or loved ones suggest as a possibility, the person has an excuse as to why this does not apply to him. Not only is this stage the result of a person's 'giving up' hope, the system often gives up hope in the person. When everyone has given up hope, no sense of possibility is felt or communicated.

The role of services is to instill hope, a sense of possibility, and to rebuild a positive self-image.

Then there are times when a person...

...is questioning the disabling power of the illness. This stage is more about 'awareness of possibility' than taking action. The person is beginning to believe that change is possible. He may not know what he can do, but the old belief that he can't do anything is beginning to crack. As Patricia Deegan says, "Maybe my life does not have to be all of this self-pity, darkness and despair." The person is not sure what the future holds, but he is beginning to believe that it may be a little brighter than he had been telling himself. And there may be something he can do that will make a difference.

My best illustration of this stage is a young woman in Las Cruces, New Mexico. We were at the end of the first day of a two-day course called “Getting a Life”. I am not sure who she was speaking to, but in the midst of a discussion she blurted out, “I am not as sick as everyone has led me to believe!” What she was saying was that she was not as ‘disabled’ by her mental illness as everyone had told her she was. I told her that she could go home now and that she did not have to come back tomorrow. She said, “I don’t understand. I have enjoyed the training and want to come back tomorrow.” I told her that she could come back, but I didn’t have anything else to teach her until she had processed and acted on what she just said.

After the training I talked with her and she told me that she had been told that she should not think about getting a job, or going back to college, or living on her own, or getting into a significant relationship, or getting married, or having children, or.... Any of those actions would be more than she could handle and may cause her to relapse. After we had talked a while, she said, “All of that just might not be true.”

This is a very crucial stage in a person’s recovery journey. This awareness – this questioning – must be followed by action. Patricia Deegan talks about this stage as the appearance of the ‘fragile flame of hope and courage’. We tend to forget the second word and only talk about the role of hope in the recovery process. Or we quote Patricia with the statement, “the fragile flame of hope”. But Patricia speaks of the “fragile flame of hope and courage”. She goes on to say, “hope must be followed by action”.

Often there is a lot of talk at this stage about various possibilities, but little real action. Maybe I could do this. The person gets right up to the edge of doing something, then chickens out. This may happen many times around many different perceived possibilities.

A visual image for this stage is a candle lighting the darkness. The fragile light of the candle is being protected by cupped hands.



At this stage something happens that causes the person to begin to **question** her beliefs about her limitations and start to believe that **change is possible**. But she may quickly realize the risks involved in making those changes and start doubting her ability to do so. The danger at this stage is held in the **Question of Risk**. When I sense that there is something I can do that may help me improve the quality of my life, how am I going to relate to the risks that might be involved in making that change? The **danger** is that the person will not take the risks required to move on with her life. She will talk herself out of doing what she says she wants to do.

Often the person has lived in her comfort zone for so long, that when she sees possibility she finds even the thought of moving out overwhelming.

Traditionally, the mental health system has not done well with helping, or even encouraging, people to risk. A person may have lived in darkness for years – not seeing any possibility. Then one day something happens and the ‘fragile flame of hope and courage’ is birthed. “Maybe I could go back to work part-time.” He decides to share this hope and possibility with someone. That person blows out the candle by saying something like, “You are not ready to go back to work. Going back to work will be too much stress for you. The doctor will decide when you are ready to go back to work.”

The danger is that the internal pressure – “I am afraid I might relapse.” – and the external pressure – “You are not ready.” – will come together in such a way as to talk the person out of taking the risk. Often the system and loved ones believe, especially if it has been difficult to get the person stabilized, that staying stable – even if the stabilized life is not meaningful - is more important than risking relapse.

The role of services is to help her see that she is not so limited by the illness and in order to move on she will need to take some risks.

Then there are times when a person...

...is challenging the disabling power of the illness. Awareness of possibility must be followed by action. If the young woman in Las Cruces did not do something that symbolized and confirmed to herself that she was not as sick or disabled as people had led her to believe, she would not move forward. If she did not act, she would more than likely stay ‘stuck’ in a life lived mainly in the mental health system – expecting others to do for her what she did not believe she could do for herself.

A lady in Georgia diagnosed with major depression spent most of the past two years in her house with the blinds pulled down. Friends and social workers visited her, but she very seldom left the house. Three of her peers convinced her to attend a three-day peer leadership training program. She attended with fear and trepidation. No one knew her story except the three peers who were supporting her. She struggled with staying or leaving throughout the training, gaining a little more confidence hour-by-hour. At the end of the three days she shared her story and thanked her peers for their support. She was given a standing ovation and a round of praise.

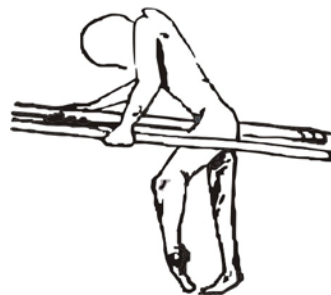
As everyone was leaving I congratulated her on her accomplishment and said that I hoped that when she got back home she would be able to get out more. She smiled,

thanked me, and said, “It won’t be easy. I will first have to let the outside world in one blind at a time. Then maybe I will think about getting out more.” She had made a commitment to change, unsure of where this was going to take her.

In this stage the person is willing to take the risk and makes a commitment to change. This is because his belief about his own situation has begun to shift. Often people talk about this shift as ‘I was sick and tired of being so sick and tired. I could not go on. I had to do something.’ In this stage a person does not necessarily have a plan of action that is moving him toward a long range or even short range goal. A person just feels that he has to do something. He cannot tolerate his life the way it is. The key at this point is to do something that breaks the pattern of doing nothing.

We often think of this as a time of small, baby steps. But ‘small, baby steps’ does not really communicate the courage it takes to move out of the comfort zone – to take the necessary risks. Deegan talks about this time as a time of “small triumphs and simple acts of courage... He shaved, he attempted to read a book, and he talked to a counselor; I rode in the car, I shopped on Wednesdays, and I talked to a friend for a few minutes.”

A visual image for this stage is a person learning to walk again, using parallel bars for support. This is often a very painful, frightening, but necessary experience.



The person begins to **challenge** the old beliefs and makes a **commitment to change**. He is willing to take the necessary

risks, but for various reasons does not get the support he needs to succeed. The danger at this stage is held in the **Question of Support**. When I decide to take the risks, how will I get the supports that I need to succeed? The **danger** is that the person will not get all of the supports he will need to be successful, move out too quickly, not succeed and retreat back into his comfort zone within the system.

Prochaska in his Stages of Change states that most people who are not successful in making the changes that they want to make jump the Preparation stage. They do not take enough time to think through everything that is going to be required of them to both make and sustain the change. They move from thinking about making a change to action without preparing for that action.

A person may not know what will be needed. His current support system may not want him to make the changes and, therefore, does not help him think through what is needed.

The role of services is to help the person take the initial steps by helping him to identify his strengths and needs in terms of skills, resources and supports.

And finally, there are times when a person...

...is moving beyond the disabling power the illness. Life takes on a sense of direction. "I know what I want to do with my life." There is a major shift in focus from the illness and its limitations to life and its possibilities. It is no longer acting to break the pattern of doing nothing. It is acting to move one in the direction that he wants his life to go. The diagnosis is not the central focus of a person's life. The central focus is his life. I believe that Dr. William Anthony was talking about this stage when he said, "The effects of mental illness are no longer the primary focus of one's life. The person moves on to other interests and activities."

A young woman in Georgia told me that there was a time when all she was aware of – all she ever thought about was her illness. Then she was introduced to Mary Ellen Copeland's Wellness Recovery Action Plan©. She became consumed with her wellness. All she thought about was all of the things she could do to stay well. Now she says she spends most of her time thinking about what she has to do at work tomorrow or what she plans to do with her friends over the weekend. Then she said, "I guess that is what chronically normal people think about." She went on to say that, of course, she had to be aware of her symptoms, her triggers, her early warning signs, etc. But her diagnosis – her mental illness - was not the central focus of her life. The central focus of her life was her life.

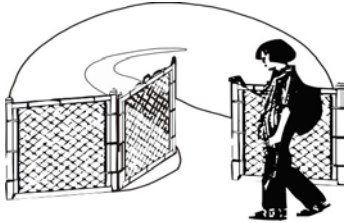
In this stage, the person is willing to start taking some actions for change that he believes will move him toward a goal – or are at least begin to create the life that he wants and will lessen his dependency on the mental health system.

There is probably no other 'illness treatment system' that takes over a person's life the way the mental health system does. It has been said that the mental health system is easy to get into but hard to get out of. I have heard people say, "I have been part of the mental health 'system' since I was 17. Or I have been in the mental health 'system' for the past 10 years." I have never heard anyone say, "I have been part of the cancer 'system' for the past 10 years." Or "I have been part of the diabetic 'system' since I was 17." They may have been a part of those systems, but they seldom talk about it in that way.

A person who lives his life 'in the mental health system' knows that there is life going on outside of the system – in the larger community, but there is a feeling that you are 'fenced in'. The life that one sees in the larger community is not for her. Life in the

system is her life. Then one day she wakes up and the gate is open. There is the possibility of life in the larger community if you will just go through this gate.

A visual image for this stage is an open gate in a fence and a person with a back pack full of recovery tools looking out. It is the awareness that there is a world of possibility out there, and it is open to your participation.



The person begins to **move beyond** the confines of the mental health system and takes **actions for change**. She may soon start questioning her abilities to take on all the responsibility involved in creating new relationships and roles outside of the system. The danger at this stage is held in the **Question of Responsibility**. Am I prepared to take on the responsibilities necessary to live in the larger community? Do I have the tools it will take to survive?

Internally she may be questioning her ability to live without all of the supports of the mental health system. Externally she may be being told that she will not be able to trust her own decision making ability, she is not ready to take on that much responsibility, she doesn't know what's best for her and she will need the system to take care of her.

The role of services is to equip her with the necessary skills, resources and supports so that she can trust in her own decision-making ability and take more responsibility for her life.

Part 5: Peer Specialist as Service Provider

You may have noticed this. The Impact of Illness Stage is the stage in which the person is relating directly to the impact of

the symptoms and the behavior brought on by the symptoms. It is a fact that she has experienced what we call 'symptoms of a mental illness' and has been diagnosed. This has happened and cannot be changed. It is a fact.

The other four stages have more to do with the relationship a person has taken or is taking to the fact that she has been diagnosed with a mental illness. These stages deal more with what she believes about herself and her future because she had that experience – the story she is telling herself. You cannot change 'fact'. You can change 'story'. Many people find themselves more disabled by the story they are telling themselves than by the illness itself.

Over the past eight years, Appalachian Consulting Group has worked in Alabama, Connecticut, Florida, Georgia, Hawaii, Idaho, Illinois, Iowa, Kansas, Louisiana, Massachusetts, Michigan, Mississippi, Missouri, South Carolina, Texas, Utah, Washington, Wisconsin, and Wyoming to set up peer specialist certification programs. We have found that people in recovery working as service providers in the system can play very helpful roles at each of these strategic and pivotal stages in this process.

People in recovery know the importance of not letting their psychiatric diagnosis define who they are. They have learned, sometimes the hard way, that they cannot turn over their identity to others who may view them through an 'illness' screen. Who best to help a person see that there is life after diagnosis?

People in recovery know the importance of moving from a sense of hopelessness and despair. When they have given up and turned her life over to the system, hope is often best communicated by someone who has had that same experience and has come through it. Their very life is a sign of possibility to both the consumer who is

struggling and the staff who are frustrated. Who best to instill hope, a sense of possibility, and to help rebuild a positive self-image?

People in recovery know the importance of taking risks. They know that they would not be where they are today without having been willing to take risks, even when they were not able to do what they had hoped they could do. They know the importance of picking themselves up, learning from those experiences and moving on. Who best to help another see that she is not so limited by the illness and in order to move on she will need to take some risks?

People in recovery know the importance of support when trying to move on with their lives. Often they have been a part of a system that has tended to take complete care of them causing them to become dependent on that system. Life in that system had become a way of life for them – and, for many, the only way of life they felt they would ever have. Who best to help the person take the initial steps by helping him to identify his strengths and needs in terms of skills, resources and supports?

People in recovery know the importance of a well stocked recovery toolkit if they are to take responsibility for all aspects of their life. Who best to equip her with the necessary skills, resources and supports so that she can trust in her own decision-making ability and take more responsibility for her life?

Recovery training, recovery services, recovery programs, recovery activities all must be about changing lives, and not about stabilizing and maintaining people. Recovery is not about fixing them or convincing them to settle for less. Recovery is about getting people in touch with the joy and wonder of their lives and their potential to live that joy and wonder.

We are in the business of changing lives. You change lives by changing belief systems.