

# Self-Determination in Mental Health Recovery: Taking Back Our Lives

*By Mary Ellen Copeland*

The most important aspect of mental health recovery for me personally is self-determination. My connection with people in the system and in recovery has convinced me that the same is true for others. In this paper I will discuss both my personal perspectives and the perspectives of others on this important topic based on many years of experience as a person, a user of mental health services, a researcher and a teacher. It will include: 1) my personal story of taking back control of my life; 2) breaking down barriers to self-determination; 3) values and ethics that support self-determination; and 4) self-determination facilitators: WRAP and Peer Support.

## **My Personal Story**

For many years I was dependent on the mental health system and other “supporters” for my well-being and to make major decisions about the important aspects of my life. I depended on this system to provide for all of my needs including food, shelter, clothing, treatment and medications. As time went on, my level of dependence increased. And through that time the circumstances of my life deteriorated. After having gotten a good education, raised a family and had a successful career, I found myself, in my mid-forties, living in a housing complex

for the elderly, on social security disability, filled with shame and despair, my records declaring that I was permanently disabled.

I remember the day all of that changed. As I was leaving my psychiatrist's office with the prescriptions for a new "soup" of medications, he said to me, "Mary Ellen, if this doesn't work, we'll try ECT." My mother had ECT many years ago, and after that she couldn't remember the time when my siblings and I were growing up. It was a huge loss to her. I was clear ECT was not a road I wanted to take. I decided that day to take back control of my life—to determine my own future. And that decision has led me on an incredible journey.

My first step was to find out how others -- who, like myself, had multiple psychiatric labels -- cope with these symptoms or difficulties as I like to call them, on a day-to-day basis. So I asked my psychiatrist. He said he would get me that information for the next time. But when, at the next appointment I asked him for that information, he told me there wasn't any information like that. There was only information on medication, hospitalization and day treatment programs.

So I developed a scheme that some people might call "grandiose", particularly for a person with a history of extreme mania and depression. I would interview people who have had these symptoms, find out how they cope, and use those skills and strategies to recover and get on with my life. In the fifteen year since I decided to take back my life, I have talked to thousand of people all over the

world. I have compiled the information they have shared with me into a mental health recovery program, have written 12 published books (distribution in the hundreds of thousands), teach others this information, and now am focusing on teaching others how to teach this information.

The most important concept that has come out of all of this—absolutely key to the recovery journey—is self-determination. Some people talk about a defining moment—that moment when they knew they had to take back control over their lives. Others describe a gradual process, an awakening. But without self-determination, people stagnate. They become more and more dependent, and more and more convinced that they will never fulfill their life dreams and goals.

It is exciting to me that mental health agencies and organizations are now recognizing the importance of self-determination—some with vigor and some more reluctantly-- and are moving to rebuild the system to reflect this change.

### **Breaking Down Barriers to Self-Determination**

There are many assumptions about “mental illness” and mental health that must change, and are changing, that will facilitate the personal process of self-determination and taking back our lives.

When I first decided to reach out for help to deal with the difficult feelings I had been having all my life, I went through a lengthy questioning process

(assessment) that had little or nothing to do with the way I was feeling. I was given a diagnosis, told what that diagnosis would mean in terms of what I could expect in my life, and given medications that I was told I must take, probably for the rest of my life. Little attention was paid to my “out of control” lifestyle, my abusive relationship and my history of childhood sexual and emotional abuse and trauma. My definition of myself changed in a very short time from person, mother, teacher, artist, writer and naturalist to “mental patient,” a person who needed others to take care of me and make decisions for me. My power was taken away and I felt different from others and alone. Unfortunately, this is a common scenario that many still experience.

What would an alternative view look like that would allow for a different outcome— an outcome that would help me get my life back, change and grow, and work toward my own goals and priorities? As before, I am dealing with difficult feelings and behaviors. I reach out for help. The person or people I reach out to assume that if I am feeling this badly, something bad has happened to me. They want to know about these things. They want to know how they can help. I am listened to. I am supported. I feel validated and safe. I am connected with peers. Together we work on seeing our feelings and behaviors in new ways and work together to find new ways of responding that foster wellness and recovery. In this trauma informed scenario I keep my personhood. I keep control of my own life. My difficulties are seen as normal human responses to bad things that have

happened to me, either recently or a long time ago. I can move forward, creating change based on my needs, dreams and goals.

For many years it has been assumed that those of us who experience psychiatric symptoms can never get well, and often get worse over time. Now we know that many, many of us have become empowered, gotten well, stayed well for long periods of time, have determined their own goals and priorities and are working toward meeting them.

Another common misperception was that those of us who experience psychiatric symptoms need to be controlled and “taken care of,” that we cannot control or take care of ourselves. Now we know that those of us who experience psychiatric symptoms can control ourselves, take care of ourselves and make choices about our own treatment and our own life. Empowerment and choice hasten recovery rather than interfere with it.

Some people have assumed that that because we have difficult times, we can't learn, and we can't make decisions, that only highly trained medical professionals understand these symptoms and can make decisions about our lives. We have always known that we can learn, and now we use our ability to learn to make good decisions for ourselves—decisions based on our own personal values and priorities—about our treatment and other aspects of our lives. Others also thought that those of us who experience psychiatric symptoms

could not advocate for ourselves, that we need others to decide for us what would be best for us, and then to advocate for us. Now we know that we can almost always advocate for ourselves. If we are having a very difficult time, we can ask for the help of family and friends who know our preferences.

Those of us who experience these symptoms were told that we should not associate with others who experience similar symptoms. Now we know that others who have experienced psychiatric symptoms can often be the best of supporters. We can understand each other and support each other in ways that are really helpful. We can “be” with our discomfort rather than needing to “fix” it immediately, and support each other through recovery. We can challenge each other to take risks and create change that would be difficult to accomplish alone.

The idea that when we are having a difficult time we need to be forcefully controlled, confined and subdued has been a widespread belief through the system for a long time. This kind of “treatment” which many of us referred to as “punishment” did not help and often made us feel worse, traumatizing us again and again, and making it much more difficult to get well. Now we know that when we are having a difficult time, there are many things we can do to help ourselves feel better. We have developed documents that instruct others on how to take care of us in ways that are really helpful when we need that help. We have advocated for the development of safe places where we are listened to, validated and supported by others who understand what we are experiencing.

In the past, it was thought that we couldn't do anything to help ourselves. Others failed to recognize our strengths and instead saw only what they considered to be our deficits. Now we are recognizing our own strengths and using those strengths to prevent and relieve symptoms and to keep ourselves well.

### **Values and Ethics that Support Self-Determination**

In order to support mental health recovery and self-determination, the system must be guided by redefined values and ethics. Through my years in this field, I have become aware of some these values and ethics. When I think the list is final, another important concept is brought to my attention that belongs on the list. Therefore, the list I am sharing with you is a "work in progress."

For these values and ethics to become entrenched in the system so we can take back our lives, each of us has to speak out whenever necessary.

The first value that literally "jumped off the page" at me as I was compiling information from my first study was *hope*. For years people had been told that they would never recover, never meet their life goals and dreams. Every time they heard this, usually from a well-meaning care provider, they felt worse and worse. Only when they began to hear messages of hope, and that others were recovering and doing the things they want to do, did they begin to realize that the same was possible for them.

Second only to hope was self-determination, called by several different names—personal responsibility, empowerment, self advocacy and self efficacy--but meaning the same thing—and absolutely essential to taking back control over our lives.

Other values and ethics that support self-determination and recovery, values and ethics that the system and each of us must personally embrace, include:

- treating each other as equals, with dignity, compassion, mutual respect and high regard.
- unconditional acceptance of each person as they are, unique, special individuals, including acceptance of diversity with relation to cultural, ethnic, religious, racial, gender, age, disability and sexual preference issues.
- avoidance of judgments, predictions, put downs, labels, blaming and shaming.
- “no-limits” thinking (the word prognosis belongs in the circular file)
- validation of personal experience.
- choices and options, not final answers.
- voluntary participation.
- each person being recognized as the expert on themselves and having a sense of their own personal value.
- use of common rather than clinical, medical and diagnostic language.

- focus on working together to increase mutual understanding and promote wellness.
- concentration on strengths and away from perceived deficits.
- basic needs like housing, food, money are taken care of when we can't meet these needs ourselves, and as we are working on our recovery.

Only with these values and ethics, can we overcome the powerlessness, fear, insecurity, sadness, isolation, worry and low self esteem, as well as the internalized discrimination, prejudice, and/or stigma which so easily become the trademark for those of us who experience these difficult symptoms.

## **Self-Determination Facilitators**

### **1. Wellness Recovery Action Planning**

One of the most profound recovery tools that I have discovered, one that is totally founded in the concept of self-determination, is the Wellness Recovery Action Plan. Back in 1997, I was working with a group of 30 people, people who had been struggling for years with various psychiatric symptoms, teaching them the recovery skills and strategies I had been learning. They found this to be somewhat helpful. However, when a woman said that she had not idea how to incorporate these tools and strategies into her life, we began working together to

develop a system to do that. And that system, now being used around the world, is WRAP.

WRAP is a plan or a process for identifying the resources that each person has available to use for their recovery, and then using those tools to develop a guide to successful living that they feel will work for them. People can develop these plans on their own, guided by the resources I have developed. However, many of them prefer to work on these plans in groups, getting ideas and feedback from others who share their experiences. Most of these groups are organized and facilitated by peers. The group process helps people move from a “learned helplessness” or “mental patient” view of themselves to seeing themselves as people with resources who can determine the course of their own lives.

WRAP development begins with building a personal Wellness Toolbox. In working on the Wellness toolbox, people come to recognize the vast resources of choices they have available for self-help and self-determination. These tools range from things like getting 8 hours of sleep every night, drinking 6-8 ounce glasses of water a day, playing with your dog, doing deep breathing exercises, avoiding sugar, and staying away from bars to spending time with peers, doing peer counseling, taking a course, joining a support group, developing leadership skills, letting go of addictions and learning new responses to troubling situations. Working together, people come up with long lists of simple, safe, effective and

often free things they can do to stay well, relieve symptoms and make their lives the way they want them to be.

This Wellness Toolbox is used to develop a personal plan that includes identifying the things to do every day to stay as well as possible, upsetting things that happen that could be “triggers”, early warning signs and signs that things have gotten much worse and developing plans using their own resources that will help them to feel better in each of these circumstances. This simple planning process has allowed numerous people to gradually or quickly take back control of their lives.

WRAP also includes a crisis plan that tells others what they want them to do to help when things become really difficult for them. The post crisis plan is a personally developed guide for the person to use when they are getting over a difficult time.

One of the key barriers to WRAP being used as it was designed and intended is that it often gets co-opted and redesigned by a program or an agency. In this process the self-determination aspects are often obliterated. Attending WRAP classes is mandated. People are told how many items they need on each list and what to put on the list. They are told they must complete their WRAP and when it needs to be completed. The care provider may insist on storing the WRAP in their office between sessions and even after it is completed, or having

a copy of it in their file. They may also insist on monitoring the person's progress, whether they are doing the things on their daily maintenance list every day, whether they used the right tools when they were triggered and so on.

It is essential that WRAP remain a self-determination tool. As such, WRAP is only WRAP when the following guidelines are adhered to:

*There is only one person who can write your WRAP—YOU.*

*You, and only you, decide:*

*If you want to write one,*

*How much time it takes you to do it*

*When you want to do it*

*What you want and don't want in it*

*Which parts you want to do*

*Who you want, if anyone, to help you with it*

*How you use it*

*Who you show it to*

*Where you keep it*

*Who, if anyone, has copies of your crisis plan*

**Copeland, M. *Mental Health Recovery and WRAP Facilitator's***

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For a person who has been in the system a long time, WRAP is often a person's first introduction to the idea that their ideas and views have value, and that

they can make their own decisions and move on with their recovery. It can be the initial step in the recovery process.

## **2. Peer Support**

Taking back control of your own life is a difficult task. It is even more difficult if you are trying to do it alone. Peer support programs that are developed by and for peers, and that are peer operated and offered instead of or in addition to traditional services can meet this need. They offer people the opportunity to get together with others who have had similar experiences, to support each other in taking back control of our lives, and to learn new ways of doing and being that replace old patterns and responses that perpetuated or worsened difficult times. In addition, they often offer leadership opportunities, education, training and job opportunities that build self-esteem and open the door to personal development and an improved quality of life.

However, if careful attention is not paid, these programs can easily revert back to the hierarchical systems that take away personal power and control. They can become just a new name for doing things the same old way. On going program evaluation and refinement by program participants is assessment is essential to insuring that these programs work toward their vision and support people in taking back control of their lives.

## **In closing**

In the years since I have been working closely with the mental health system, I have seen phenomenal movement toward a system that is truly focused on recovery and self-determination. Thankfully we are light years away from the time in the late forties and early fifties when my mother spent 8 years confined and controlled in a horrific institution. On the one hand I am convinced that we have come so far and so many people are empowered, that we can never return to those infamous days. On the other hand, I know that we all must be vigilant, especially in these times, to retain the gains we have made and continue our progress.

## Resources

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