

**CERTIFIED**

**PEER**

**SPECIALIST**

**PREP**

**Foundations  
for CPS Work  
& Training**

*Because we've been there, done that  
,....and moved beyond*

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# UNIT 1

## Introduction and Overview

### Trainer's Notes

### *Unit* Goals and Objectives

- o Introduction to the class
- o Overview of the course

### *Summary* of Main Ideas

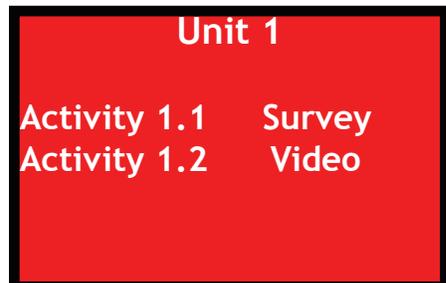
- o Class provides foundation needed for CPS training
- o Class includes videos, readings, exercises and doing things in the community
- o All activities are related

### *Materials*

- o Workbook
- o Laptop and projector
- o Screen
- o Flip chart paper (preferably ones that stick to the wall)
- o Markers (various colors)
- o Pens (one for each student)
- o Snacks
- o Toys
- o Name tags or tents

### *Preparation:*

- As a facilitator, you always want to spend time before the class to review the materials, plan out your time and decide how you'd like to do exercises, etc
- Review Video 1: Welcome and Introduction
- Be prepared to answer any questions about the class format, what it will cover, etc.





## INTRODUCTION

Welcome to the Certified Peer Specialist (CPS) preparatory training. This training is for anyone who is thinking about taking the CPS course at some time in the future. The CPS is a rigorous course because the CPS job requires someone to have many skills. People with stronger foundations are more likely to get accepted into the CPS class, so we'll be exploring these in this class.

This training covers a variety of topics that create the foundation of the CPS training course. As those of us that live on the coast know, houses built on sand rather than on strong foundations eventually fall apart, victim to the power of storm and tides around them.

Similarly, when we take a training course to prepare for an area of work without having a solid foundation in peer practice, recovery systems and our own personal wellness, we can also fall apart, figuratively or literally.



So, this course was created as a way for people to strengthen certain foundations to increase the likelihood of success in the CPS training and work as a CPS.

The training can be done in a number of different ways. Ideally, current CPSs will choose to offer this as a course at RLCs and/or within agencies. Each unit has training notes at the beginning and throughout the unit to assist anyone taking on this leadership role. (Note: this shouldn't be facilitated by someone without lived experience and not familiar with CPS practice).

Several Units include a video presentation that overviews all the main learning points. In addition, there are readings from different people with lived experience as well as people who have studied different topics that are included in that unit.

Finally, and most important, there are exercises and activities to do on your own or with others. Some suggest that you actually go somewhere and observe something, talk to someone or do something.



Some of these activities may feel difficult to you. They were put into the course because a CPS has to do these kinds of things in their everyday work, so this is a good place to begin to learn how to get beyond your “comfort zone.”

The course doesn’t have any specific time limits to do things. It’s meant to be self-paced, so you can move quickly through things that you’re already experienced with and take more time with things that are new and unfamiliar, or a little scary. The point is to build the foundation, not finish the course. It’s not a ‘race to the finish,’ but instead a change to remind yourself of all that you do know, and build on that.

Throughout the course, you’ll have the opportunity to reflect on what was easy and what was difficult. Reflection and self-assessment will support you to continue to build on and develop strengths by creating your own ongoing action plan. Each of these activities prepare you for the CPS class and CPS work because our work always relies on sharing our journeys, and especially the journeys in recovery. Hopefully, in the end, you’ll find them fun and interesting despite the challenge.

As CPSs and peer workers, our “credential” for the job is our lived experience related to receiving a mental health diagnosis, living with the stigma and discrimination related to those labels, and tapping into our human resiliency to rewrite the scripts of our lives. The stories of the journeys to our own recoveries are the primary tool we rely on in our work.

Like any tool, we have to know what it is, what different versions exist, how it works best, etc. if we’re going to use the tool effectively in our work. To support you to do this, the course will involve exploring our own unfolding journeys and how these journeys can support others, both people and institutions, in their own recovery.

We’ll discuss areas such as self-definition and self-determination, inside and “outside the box” travels, pathways to self-empowerment and journeys that we share together. We’ll look at the REALITY of experiences, how we self-REFLECT and REFRAME experiences, and, then, ways we RELATE the story to others.

**ACTIVITY 1.1 SURVEY:** Complete the survey below. It’s called the “Recovery Assessment Scale<sup>1</sup>.” There’s no right or wrong answers. It’s simply a way to explore what feelings and beliefs you have in different components of recovery. We’ll revisit this survey throughout the course.

**TRAINER NOTE:** As you introduce people to the survey, remind them that there are no wrong answers - this is just their own opinion. As course facilitator, you can have people turn in the surveys to you, report general findings to the class, and have them do the same survey later for comparison. This is one of many possible options and isn’t a required format. Just having people do the survey is sufficient.

The survey is also a way for you to begin to explore and reflect on your own unfolding recovery journeys.

## Recovery Assessment Scale (RAS) (modified)

Below is a list of statements that describe how people sometimes feel about themselves and their lives. Please read each one carefully and circle the number to the right that best describes how much you agree or disagree with that statement. Circle only one for each statement.

Scale: 1=Strongly Disagree 2= Disagree 3= Not Sure 4 = Agree 5=Strongly Agree

	ITEM	1	2	3	4	5
1	I have a desire to succeed					
2	I have my own plan for how to become and stay well					
3	I have goals in my life that I want to reach					
4	I believe I can meet my own current personal goals					
5	I have a purpose in life					
6	Even when I don't care about myself, other people do					
7	I have learned about many different perspectives on "mental illness" and emotional distress.					
8	I have a variety of tools and strategies that I use to promote my own wellness.					
9	I like myself					
10	I am in charge of my own life, though I may ask others to support me along the way.					
11	I am becoming who I want to become					
12	I am the person most responsible for my own recovery journey					
13	I am hopeful about the future					
14	My treatment team is only a small part of my life and wellbeing					
15	I make sure that I have the chance to have fun on a regular basis					
16	I continue to develop new interests					
17	When I experience emotional distress, I have several things I can do that help me feel better.					
18	I gather information and ask questions so I can make informed decisions, especially around any treatment.					
19	I believe that everyone, including me, has the potential for a full and complete recovery					
20	I am willing to ask to help					
21	I know when to ask for help					
22	Being able to work is important to me					
23	I can handle 'life on life's terms'					
24	Fear doesn't stop me from living the way I want to					
25	Almost always, a "mistake" can be reframed to a learning experience					

<sup>1</sup> "Recovery Assessment Scale" Giffort, D.; Schmook, A.; Woody, C; Vollendorf, C; and Gervain, M. Construction of a Scale to Measure Consumer Recovery. Springfield, IL: Illinois Office of Mental Health, 1995.

## ACTIVITY 1.2: Unit 1 Video

The video provides more of an overview and orientation to the course.

As you go through the course, please note any thoughts on what you like and what you think should be added in.

There will be an evaluation at the end, and your feedback is important as we continue to build on this basic course.

Enjoy !!!



## Unit 2: Journey of Hope & Empowerment Trainer Notes

### *Unit Goals and Objectives:*

- Understand concept of Empowerment
- Recognize the link between Hope and Empowerment
- Identify 3 reasons why empowerment in personal health, including mental health, is important
- Identify 3 practices in mental health systems that support and facilitate empowerment.
- Identify 3 personal strategies that increase empowerment

### *Summary of Main Ideas:*

- Hope and Empowerment are critical steps in a recovery journey
- We can't support others to become empowered if we are not empowered in our own life.
- We become empowered through self-exploration and curiosity

### *Materials*

- Workbook
- Laptop and projector
- Screen
- Flip chart paper (preferably ones that stick to the wall)
- Markers (various colors)
- Pens (one for each student)
- Snacks
- Toys
- Name tags or tents

### *Preparation:*

- Review Video 2: Inner Wisdom
- Be fully familiar with the material prior to the class so you can answer questions and/or facilitate classroom conversations

Unit 2	
Activity 2.1	Exercise
Activity 2.2	Video
Activity 2.3	Exercise
Activity 2.4	Videos
Activity 2.5	Exercise
Activity 2.6	Readings
Activity 2.7	Exercise



## Journey of Hope & Empowerment

Receiving a psychiatric diagnosis can be overwhelming and devastating for people. Even when someone initially feels relieved to have a name for what's going on, it's often replaced by despair not too long afterwards. Unfortunately, psychiatric diagnoses are accompanied by:

- Misunderstandings about what this “thing” (mental illness diagnosis) is
- Stigma & internalized stigma
- Discrimination
- Social Alienation

Society has historically shunned people experiencing emotional distress or altered states. As a result, people have been generally willing (and relieved) to turn over the “care” of “the mentally ill” to the medical profession, without questioning if this is the best route for people having difficulties. This has led to a very large psychiatric system that can sometimes offer “treatments” more harmful and debilitating than the original distress experienced by someone.

One area that can be impacted over time is our sense of capacity or desire to be in charge of our lives. Being constantly told that any less-than-perfect choice is proof of how “sick” we are, being put into places where compliance is required on everything large to small, and being put on medications that can blunt or alter our everyday emotions can lead us to lose touch with what we actually like and don't like, what pleases us or bothers us. Messages to be “realistic” and keep our goals in line with the limitations of our “illness” can strip us of hope for the future. All of this together can eventually lead to what's known as “learned” or “taught” helplessness.

“Taught Helplessness” is created in far more subtle ways. Very often, well-meaning people say and do things that strip us of the opportunities to use our decision-making skills and, like a muscle that loses its’ strength from non-use (atrophy), we find that we lose the confidence in running our own life. Things like “You’re appointment is on Friday,” “the van for the grocery store leaves at 10:00,” “you can only get food from the kitchen until 10:00 am,” “Let me call them for you,” etc. The more our life is structured around the rules and expectations of others, the more we are taught to default to others for basic life choices.

### **“Culture of Patienthood”**

The emotional impact of seeing no future (hopelessness) and having no faith in our own ability to do something to make a change in our situation(s) (helplessness) closes doors to everyday life activities that bring meaning and purpose, like employment, social involvement, spiritual lives or family lives.

The opposite of being hopeful is experiencing hopelessness. Unfortunately, all too often we are witness to people who have lost all hope that they can ever live out their dreams. As a matter of fact, it seems that many people don’t even dare to dream. When we ask what a person’s hopes, dreams, goals, and desires are, sometimes we hear “I don’t know.” That tells us that this person may be feeling hopeless.

What contributes to this feeling of hopelessness that people with mental health and addiction challenges can experience? One of the factors may be the stigma of having a diagnosis that can translate into self-stigma and a patient identity.

### **Stigma:**

Something judged by others as a mark of disgrace or shame and which can set one apart from everybody else

## **Self-Stigma:**

....when a person begins to define or see themselves in a stigmatizing way. For example, when you are treated as incapable due to a mental health challenge, you may start to see yourself as incapable and begin to behave as though you are, relying on others to make all of your decisions for you. An example of a self-stigmatizing identity is that of a patient.

## **Activity 2.1: Exercise: Culture of Patienthood**

- What does it mean to be a patient?
- How do you spend your time?
- Who is in control of your life?
- How does this impact what you think about yourself?
- How does it affect your thoughts, confidence, behavior and beliefs?

## “To Be A Mental Patient”

- To be a mental patient is to be stigmatized, ostracized, socialized, patronized, psychiatrized.
- To be a mental patient is not to matter.
- To be a mental patient is to wear a label, a label that never goes away, a label that says little about what you are and even less about who you are.
- To be a mental patient is to act glad when you're sad and calm when you're mad.
- To be a mental patient is to participate in stupid groups that call themselves therapy -- music isn't music, its therapy; volleyball isn't a sport, its therapy; sewing is therapy; washing dishes is therapy.

- *Rae Unzicker*  
*Pioneer in the Disability Rights Movement*

Being denied power in areas that we're fully capable of having our own power can also be demeaning and, over time, chip away at our dignity and self-respect. Again, our sense of a personhood gets diminished, replaced with some form of “mental illness” self-definition. This is often stated as, “I became my diagnosis.”



## Activity 2.2: “Road of Hope & Empowerment” Video

Watch video 2: Road to Hope and Empowerment

The video discussed a process that many of us use, whether we’re actually thinking through steps or not, to walk different recovery journeys and use the information from the journey to better our life. As peer workers, the ability to reflect back on the journey after the fact is vital, because it’s only then that we can create a meaningful story to share with another for the purpose of inspiring hope, proving recovery, etc.

As important is the very idea of being curious around those areas that we’ve been taught to just accept. We’ve taught to elevate doctors and the medical profession to all-knowing experts. We don’t see ourselves as knowledgeable enough to question the doctor’s opinion, or even have a conversation. We just see ourselves as passive recipients of the expertise from the medical professional. This is part of our culture.

Also part of our culture is the idea that a pill will fix everything. On TV, you probably see a commercial for some drug every hour, if not more. When we’re miserable, we want to believe that this is the answer - who wouldn’t. But part of the empowerment road is the underlying curiosity that leads us to question things - even and especially those things that seem hardest to question. We’ll be talking more about this in the next Unit.

**T**RAINER NOTE: *The exercise below can be done in a variety of ways. People can do it on their own, followed by group discussion. Pairs or small groups can get together after people have had a little time to think of an experience and write brief notes. The framework questions can also be used for a larger assignment, either homework or in pairs. This would also be a good exercise to be done with multi-media or arts. People could take photos of how things felt at different points in the process, or create collages, etc.*

## **Activity 2.3: Exercise**

*Think about any recovery journey you've taken, for example from lack of power to empowered, from "status quo" beliefs about "mental illness" to wider perspectives, from "I'm an ill broken person" to "I'm a whole person," etc. Go through each step of the process discussed in the video and try to identify what took place in that step.*

### **Journey:**

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1. What occurred that gave you at least a slight splash of hope? What led you to think it might be possible to have things change and improve?
2. As you thought about the issue with your "I'm Curious" glasses on, what questions did you come up with or have?
3. How did you gather information? From whom or what did you get more knowledge? How did you know where to look?
4. How did you figure out if the new information fit you? What did you do to experiment or practice, using trial and error?
5. What new questions came to mind as you answered your original questions. Did these support you to continue to walk down a recovery road?

*“Empowerment happens when a person who is seen as the problem begins to see him or herself as part of the solution.”*

(Saul Alinsky quoted in Campbell and Leaver, 2003)

It takes a certain amount of empowerment to walk any recovery journey, such as the one you identified in the exercise above. Empowerment is a process, not a destination, and is generally something that we build within us. Other people can create an environment where we can exercise our power, but they can't endow us with that inner sense of personal power. It is something we have to nurture and feed, like a fledgling plant, so it will grow and thrive.

The concept of “empowerment” comes directly out of the peer movement, once known as the “consumer/survivor/ex-patient” movement. Threads to the movement emerge from as far back as the 1700 and 1800s, but took hold in a meaningful way in the 1960's, along with a variety of other “rights” and “pride” movements (disability rights, gay rights, gay pride, mad pride, civil rights, womens' rights).

The peer movement was a civil rights movement, fighting against forced treatment and general abusive conditions within psychiatric hospitals, where most people received treatment at the time.

It was also a human rights movement, fighting against the hierarchy of power inherent in the system. That is, the professional makes the decisions and the person using services complies. There was no room for a genuine relationship between provider and person using services, and, in fact, people using services were not seen as having the capacity or knowledge to have a any voice or opinion at all. The peer movement fought against this “paternalistic” system - one that treats the service user as just as diagnosis and not individuals who should be active in their own treatment and driving their own lives.

The peer movement was also a myth-busting movement, challenging conventional wisdom that “mental illness” means life-long chronic debilitating illness. People with lived experience, backed by researchers who had proved recovery through actual studies, fought to be given the respect they were due as people recovering or recovered. They said “Nothing About Us Without Us” *because* what we have to say is valuable and important.

Finally, the peer movement was a transformative movement, saying that people recovering together offered each other solutions that were often more meaningful than those offered by the psychiatric community.

Judi Chamberlin, a leading figure of the c/s/x movement, worked with people at the Boston University Center for Psychiatric Rehabilitation, created an empowerment scale<sup>1</sup> that includes items, such as:

1	I can pretty much determine what will happen in my life
2	Getting angry about something can be helpful
3	I am usually confident about the decisions I make
4	I see myself as a capable person
5	I'm usually able to overcome barriers
6	Experts aren't always in the best position to decide what people should do or learn
7	I feel I am a person of worth, at least on an equal basis with others
8	People have the right to make their own decisions, even if they are bad ones

## **Activity 2.4: Videos,**

*Watch the following videos, with the empowerment components listed above in mind. How did each of these people embody some or all of these elements in their work?*

<sup>1</sup> Rogers, S., Chamberlin, J., Ellison, M.L. and Crean, T. (1997) A consumer constructed scale to Measure Empowerment among users of mental health services. *Psychiatric Services*, 48:8, 1042-1046

## **Judi Chamberlin, *Her Life, Our Movement***

<http://www.youtube.com/watch?v=FGT4xJXgmoE&list=PLE78D0957AF0460B1>

Judi Chamberlin is one of the leaders of the peer movement. Her landmark publication, “On Our Own” was first published in 1977, in which she advocated for peer-to-peer services. It has continued to be reprinted over the years and is currently available at the National Empowerment Center ([www.power2u.org](http://www.power2u.org)). Judi joined forces with people fighting for rights within the physical disability community as well, and played a major role in ensuring that mental health was included in international disability rights policies.

## **Bonfire Madigan Shive**

<http://www.youtube.com/watch?v=nws-WScj2Js&feature=share&list=PLE78D0957AF0460B1>

Composer, performer, musician and mental health activist Bonfire Madigan Shive. Also, author of “Living Through This”

## **Sylvia Caras**

<http://www.youtube.com/watch?v=FiC877p6ORw&feature=share&list=PLE78D0957AF0460B1>

Sylvia is the founder of [www.peoplewho.org](http://www.peoplewho.org) - an e-community of people who experience “mood swings, fear, voices and visions.” Sylvia is currently the International Disability Alliance Information and Communication Technology Liaison. She began e-support at [www.peoplewho.org](http://www.peoplewho.org)

## **Mary Nettle**

[http://www.youtube.com/watch?v=\\_if4Wyh\\_CTg&feature=share&list=PLE78D0957AF0460B1](http://www.youtube.com/watch?v=_if4Wyh_CTg&feature=share&list=PLE78D0957AF0460B1)

Mary Nettle began using mental health services in 1978 and became a mental health user consultant in 1992. She is involved in presenting the user perspective in all aspects of mental health with a particular interest in user led research.

**T**RAINER NOTE: *The exercise below can be done in a variety of ways. People can do it on their own, followed by group discussion. Pairs or small groups can get together after people have had a little time to think of their experiences, either in the current class or next class. It can also be incorporated into a homework assignment.*

## **Activity 2.5: Exercise**

*Answer each of the following questions, regarding your own experiences:*

1. Empowered persons have a sense of control over their choices and their lives. How have you been able to exercise control over your own life? How have others supported you to be in control of your own life?
  
2. Empowered persons have the skills and capacities to make informed choices about decisions large and small. What skills have you developed and how were you able to develop these skills.
  
3. Empowerment is directly related to feelings of self-worth, self-esteem, and self-confidence. Do you resonate with these feelings? What supported you to develop these positive feelings?
  
4. How do the ideas of being a “helper” and supporting “empowerment” align or not align ? (We’ll discuss this more in later sections).

## Activity 2.6: Readings

Read the recovery stories below, considering the idea of personal empowerment and moving beyond “learned hopelessness.”



### **Emily Grossman's Story**

*Growing up I did not struggle with mental health at all. I did well in school, had friends and was involved in activities. A New Jersey native, I was excited about going away to college at Emory University in Atlanta. When I went to college things went well at first, but then I started experiencing symptoms that I didn't understand. I had panic attacks which became so severe that I couldn't go to class or even get out of bed. I remember feeling embarrassed living in the dorm where people could see my decline. My mom came down to see if she could help.*

*My mom and I decided that I would go to a therapist and a psychiatrist. I was getting treatment but was also becoming more and more embarrassed. At one point, I tried to take pills to overdose but I spit them out right away. Still - this was not a good sign.*

*So I went home and was diagnosed with bipolar disorder. Despite being in and out of treatment programs and hospitals throughout my college career, I was able to graduate in about five years.*

*I asked myself, "What comes next?" I did not know. Having been in an abusive relationship in college, I was left with a post traumatic stress disorder. I stuttered at job interviews. My confidence was shot.*

*Finally, I found a teaching assistant position in New Hampshire with Americorps. I thought it would be a good employment opportunity and a chance to get away from my problems. Instead, my problems got worse. I gave up and went off of my medications. It was the only time in my adult life that I stopped seeing a therapist. I was hopeless there and wanted no part of getting help. My parents took me home.*

*When I returned, I lived in supportive housing with people older and sicker than I was. I did not have a job - it was an all-time low.*

*Again, I became motivated, inspired by the book Awaken the Giant Within by Anthony Robbins, which was about becoming your "best self." I started to think "why not me?" I got to the point that I felt I had to recover - I couldn't do "this" any more.*

*I found my first and second jobs, which were at tutoring centers, but I lost each of them after about nine months.*

*I applied to graduate school, got into Columbia Teachers College to prepare myself to pursue my dream of inspiring children and deferred it for a year, depleted by concerns about managing such a challenging goal. But I had something to prove to myself and my family. So I worked very hard on my recovery and became well enough to attend Columbia the next year, which turned out to be the best year of my life! I loved my classes, and my friends and I found Buddhism, which was a big thing for me. I started to solidify my career - it felt good.*

*Following, I taught for three years in New Jersey. My mental health was pretty good but I started to become stressed toward the end of that time.*

*I attended CORE Training from MHANJ's Consumer Connections because I wanted to switch into the mental health field. Often when you are in recovery, you see those who are sick but not getting well, especially if you are in a treatment center. Consumer Connections helped me to see that there were others who struggled with their mental health and were in recovery. They also gave me such a good basis of knowledge. I understood my own perspective but they introduced me to the science behind it. CORE training gave me the confidence that I needed to switch into the mental health field.*

*After I finished CORE I got my first job, which was as a Peer Provider at Care Plus NJ. I worked with social workers and psychiatrists, helping consumers to get well. It was empowering to be able to help other people recover and know that my experience meant something.*

*I wrote a book about how to recover from mental illness, entitled, There and Back Again. Then I wrote a second book for children called, There and Back Again, Too.*

*I also started a business called The Dream Team Coaches, which offers life coaching for teens and young adults struggling with mental health.*

*While working at Care Plus NJ, I made a connection to the Mental Health Association in New Jersey and was offered a job as Peer Navigator for Employment Works! I have been doing this since 2010.*

*This year I accomplished one of my dreams -- running a half marathon. Thanks to the sponsorship family and friends, I was able to raise over \$1100 for MHANJ. It was very rewarding.*

*My mental health has been stable for a good six years or so. I haven't struggled, I see therapists and my medication is working out. I am proud to be active, working and helping people through my life experience.*



## National Empowerment Center - Articles

### Confessions of a non-compliant patient

*By Judi Chamberlin*

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A famous comedian once said, "I've been rich, and I've been poor, and believe me, rich is better." Well, I've been a good patient, and I've been a bad patient, and believe me, being a good patient helps to get you out of the hospital, but being a bad patient helps to get you back to real life.

Being a patient was the most devastating experience of my life. At a time when I was already fragile, already vulnerable, being labeled and treated only confirmed to me that I was worthless. It was clear that my thoughts, feelings, and opinions counted for little. I was presumed not to be able to take care of myself, not to be able to make decisions in my own best interest, and to need mental health professionals to run my life for me. For this total disregard of my wishes and feelings, I was expected to be appreciative and grateful. In fact, anything less was tacked as a further symptom of my illness, as one more indication that I truly needed more of the same.

I tried hard to be a good patient. I saw what happened to bad patients: they were the ones in the seclusion rooms, the ones who got sent to the worst wards, the ones who had been in the hospital for years, or who had come back again and again. I was determined not to be like them. So I gritted my teeth and told the staff what they wanted to hear. I told them I appreciated their help. I told them I was glad to be in the safe environment of the hospital. I said that I knew I was sick, and that I wanted to get better. In short, I lied. I didn't cry and scream and tell them that I hated them and their hospital and their drugs and their diagnoses, even though that was what I was really feeling. I'd learned where that kind of thing got me - that's how I ended up in the state hospital in the first place. I'd been a bad patient, and this was where it had gotten me. My diagnosis was chronic schizophrenia, my prognosis was that I'd spend my life going in and out of hospitals.

I'd been so outraged during my first few hospitalizations, in the psychiatric ward of a large general hospital, and in a couple of supposedly prestigious private psychiatric hospitals. I hated the regimentation, the requirement that I take drugs that slowed my body and my mind, the lack of fresh air and exercise, the way we were followed everywhere. So I complained, I protested, I even tried running away. And where had it gotten me? Behind the thick walls and barred windows and locked doors of a "hospital" that was far more of a prison than the ones I'd been trying to escape from. The implicit message was clear: this was what happened to bad patients.

I learned to hide my feelings, especially negative ones. The very first day in the state hospital, I received a valuable piece of advice. Feeling frightened, abandoned, and alone, I started to cry in the day room. Another patient came and sat beside me, leaned over and whispered, "Don't do that. They'll think you're depressed." So I learned to cry only at night, in my bed, under the covers without making a sound.

My only aim during my two-month stay in the state hospital (probably the longest two months of my life) was to get out. If that meant being a good patient, if that meant playing the game, telling them what they wanted to hear, then so be it. At the same time, I was consumed with the clear conviction that there was something fundamentally wrong here. Who were these people that had taken such total control of our lives? Why were they the experts on what we should do, how we should live? Why was the ugliness, and even the brutality, of what was happening to us overlooked and ignored? Why had the world turned its back on us?

So I became a good patient outwardly, while inside I nurtured a secret rebellion that was no less real for being hidden. I used to imagine a future in which an army of former patients marched on the hospital, emptied it of patients and staff, and then burned all the buildings to the ground. In my fantasy, we joined hands and danced around this bonfire of oppression. You see, in my heart I was already a very, very bad patient!

One of the things I had already discovered in my journey through various hospitals, which culminated in my involuntary commitment to the state hospital, is that psychiatric drugs didn't help me. Every drug I was given made me feel worse, not better. They made me fat, lethargic, unable to think or to remember. When I could, I refused drugs. Before I got committed, I used to hide the pills in my cheek, and spit them out when I was alone. In the state hospital, I didn't dare to try this trick. I dutifully swallowed the pills, hating the way they made me feel, knowing that, once I was free, I would stop taking them. Once again, I was non-compliant in thought before I could be non-compliant in deed.

Now I want to make one thing very clear here. I am not advocating that no one should take psychiatric drugs. What I am saying, and I want to make sure this point is understood, is that each individual needs to discover for himself or herself whether or not the drugs are part of the solution, or part of the problem. Many people I know and respect tell me that they would not be where they are in their recovery were it not for the particular drugs that they have found work for them. On the other hand, many others, of which I am one, have found that only when we clear ourselves of all psychiatric drugs do we begin to find the road to recovery. We need to respect these choices, and to understand that there is no one single path for all of us.

Psychiatric drugs, like all drugs, have side effects. If the positive effects outweigh the negative effects, then people will generally choose to take the drugs. When the negative effects, however, outweigh the positive ones, then the choice not to take the drugs is a good and reasonable one. Side effects can be more easily tolerated when one is gaining something positive in return. Let me give an example from my own experience. Every day, I take anti-inflammatory drugs to control the symptoms of arthritis. Without these drugs, I would be in pain much of the time, and find it difficult to move easily. I'm willing to put up with the danger of developing ulcers (and I take another drug to help protect my stomach), because the cost/benefit ratio works out in my favor. If, on the other hand, the anti-inflammatory drug didn't relieve the arthritis pain, then the cost/benefit ratio would go the other way, and I would stop taking the drug and discuss with my rheumatologist what other approach to try.

Here is the key difference between what happens to psychiatric patients and what happens to people with physical illnesses. With my rheumatologist, and with my lung doctor (I also have a chronic lung disease). I am a full partner in my own treatment and recovery. I am consulted, listened to, and given the information I need to make informed choices. I acknowledge that the doctors have expertise that I lack, and they, in turn, acknowledge that I have information about the workings of my own body that they need to guide them in their recommendations. Sometimes, we disagree. Then we talk about it. Sometimes I take their advice, while other times I don't.

Psychiatric patients, on the other hand, are usually assumed not to know what is best for us, and to need supervision and control. We are often assumed to be talking in code; only so-called "experts" can figure out what we really mean. A patient who refuses psychiatric drugs may have very good reasons - the risk of tardive dyskinesia, for example, or the experience of too many undesirable negative effects. But professionals often assume that we are expressing a symbolic rebellion of some sort when we try to give a straightforward explanation of what we want, and what we don't want. I'm sure you've all heard the many psychiatrist jokes that feature the punch line, "Hmm, I wonder what he means by that?" Well, doctor, I want to tell you, we usually mean just what we are saying. In the slogan of the women's movement: "What part of no don't you

understand?"

I consider myself a very lucky person. I don't think that I have some special talent or ability that has enabled me to recover when so many others seem stuck in eternal patienthood. I believe that recovery is for everyone. In the words of the mission statement of the National Empowerment Center, we: carry a message of recovery, empowerment, hope and healing to people who have been diagnosed with mental illness. We carry that message with authority because we are a consumer-run organization and each of us is living a personal journey of recovery and empowerment. We are convinced that recovery and empowerment are not the privilege of a few exceptional leaders, but rather are possible for each person who has been diagnosed with a mental illness. Whether on the back ward of a state mental institution or working as an executive in corporation, we want people who are mental health consumers to regain control over their lives and the resources that affect their lives.

One of the elements that makes recovery possible is the regaining of one's belief in oneself. Patients are constantly indoctrinated with the message, explicit or implicit, that we are defective human beings who shouldn't aim too high. In fact, there are diagnostic labels, including "grandiosity" and "lack of insight," to remind us that our dreams and hopes are often seen as barriers to recovery instead of one its vital components.

Professionals and patients often have very different ideas of what the word "recovery" means. Recovery, to me, doesn't mean denying my problems or pretending that they don't exist. I have learned a lot from people with physical disabilities, who think of recovery not in terms, necessarily, of restoring lost function, but of finding ways to compensate or substitute for what one may be unable to do. Some of the most able people I know, in the true sense of the word, are activists in the physical disability movement - they may not be able to see, or hear, or move their limbs, but they have found ways to do the things they want to do despite these difficulties, and despite those professionals who advised them not even to try. Without our dreams, without our hopes for the future, without our aspirations to move ahead, we become truly "hopeless cases."

I often hear professionals say that, while they support the ideas of recovery and empowerment in principle, it just won't work for their clients, who are too sick, too disabled, too unmotivated. Whenever I hear these objections, I want to know more about what kinds of programs these professionals work in, and what goes on there. I know that the professionals who knew me as their patient thought the same things about me. That's the dilemma of the "good patient." A good patient is one who is compliant, who does what he or she is told, who doesn't make trouble, but who also doesn't ever really get better. A "good patient" is often someone who has given up hope and who has internalized the staff's very limited vision of his or her potential.

Now, again, I want to make myself clear. I'm not saying that mental health professionals are evil people who want to hold us all in the grip of permanent patienthood, and who don't want us to get well. What I'm saying is that there's something about being a "good patient" that is, unintentionally, perhaps, incompatible with recovery and empowerment. When many of us who have become leaders in the consumer/survivor movement compare notes, we find that one of the factors we usually have in common is that we were labeled "bad patients." We were "uncooperative," we were "non-compliant," we were "manipulative," we "lacked insight." Often, we were the ones who were told we would never get better. I know I was! But twenty-five years of activism in the consumer/survivor movement has been the key element in my own process of recovery.

Let's look at this word "compliance." My dictionary tells me it means "acquiescent," "submissive," "yielding." Emotionally healthy people are supposed to be strong and assertive. It's slaves and subjects who must be compliant. Yet compliance is often a high value in professionals' assessments of how well we are doing. Being a good patient becomes more important than

getting well. It's like the healthy woman/healthy person dilemma. Psychological researchers have found that while emotionally healthy adults, gender unspecified, are supposed to be assertive and ambitious, emotionally healthy women are supposed to put others' needs before their own. If you're a woman and fulfill the stereotyped "woman's role," then you're not an emotionally healthy person. If, on the other hand, you are strong and assertive, then you can be labeled as not being an emotionally healthy woman.

Getting better, we were informed by staff, meant following their visions of our lives, not our own. Let me give you an example, from a book called Reality Police by Anthony Brandt:

*[Brandt says] I was thought to be a hopeful case, for example, so the doctor assigned to it worked up a life plan for me...I was to stay in the hospital three months or so to stabilize my life, she said. When I seemed up to it, I would go to work in the hospital's "sheltered workshop" where I would make boxes for IBM and be paid on a piecework basis. When I had made enough boxes I would then be moved to the halfway house in Kingston, across the Hudson, where they would arrange a job for me in a special places called Gateway Industries established for the rehabilitation of mental patients. There I would presumably make more boxes. Eventually I might move out of the halfway house into my own apartment.*

What Anthony Brandt's doctor didn't know was that Brandt was not a "mental patient" at all. He was a writer who had feigned the symptoms of mental illness in order to find out first hand what the life of a mental patient was like. He had a successful career and a real life that he could return to. He didn't have to accept limited view of his abilities as potential. Most real mental patients are not so lucky.

Anthony Brandt wrote his book in the mid '70's, but what happened to him unfortunately continues to happen today. All those "unmotivated clients" I keep hearing about are the ones who are on a silent sit-down strike about others' visions of what their lives should be like. When I ask professionals what it is that their clients are "unmotivated " about, it usually turns out to be washing floors or dishes, on the one hand, or going to meaningless meetings on the other. Would you be "motivated" to reveal your deepest secrets to a stranger, for example, someone you have no reason to believe you can trust with this sensitive information? And, more important, should you be "motivated" to do so? People, in general, are motivated to do things that they want to do, or which will get them things which they want. Just because someone has a diagnosis of "mental illness" doesn't change that fundamental fact of human nature. All the time and energy that mental health professionals seem to put into "motivating" their clients to do things they don't want to do would, I think, be better spent helping clients to figure out what things they want for themselves, and the strategies to achieve them.

We need to start encouraging people to dream, and to articulate their own visions of their own futures. We may not achieve all our dreams, but hoping and wishing are food for the human spirit. We, all of us, need real goals to aspire to, goals that we determine, aims that are individual and personal. I feel crushed when I visit programs that are training their clients for futures as residents of halfway houses and part-time workers in menial jobs. And if I, a visitor, feel my spirit being crushed, how do the people trapped in those programs feel?

Researchers have asked clinicians what kinds of housing, for example, their clients need, and been told that congregate, segregating housing was the best setting. At the same time, the researchers have asked the clients directly what kind of housing they want, and been told that people would choose (if they were given the choice) to live in their own homes or apartments, alone, or with one other person they had chosen to live with. At the end of the year, the researchers found, the clients who got the kind of housing they wanted were doing better than the clients that got the housing that was thought to be clinically appropriate. Helping people to reach

their goals is, among other things, therapeutic.

One of the reasons I believe I was able to escape the role of chronic patient that had been predicted for me was that I was able to leave the surveillance and control of the mental health system when I left the state hospital. Today, that's called "falling through the cracks." While I agree that it's important to help people avoid hunger and homelessness, such help must not come at too high a price. Help that comes with unwanted strings - "We'll give you housing if you take medication," "We'll sign your SSI papers if you go to the day program" -is help that is paid for in imprisoned spirits and stifled dreams. We should not be surprised that some people won't sell their souls so cheaply.

Let us celebrate the spirit of non-compliance that is the self struggling to survivor. Let us celebrate the unbowed head, the heart that still dreams, the voice that refuses to be silent. I wish I could show you the picture that hangs on my office wall, which inspires me every day, a drawing by Tanya Temkin, a wonderful artist and psychiatric survivor activist. In a gloomy and barred room a group of women sit slumped in defeat, dresses in rags, while on the opposite wall their shadows, upright, with raised arms and wild hair and clenched fists, dance the triumphant dance of the spirit that will not die.

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# Personal Stories



## Oryx Cohen

"Meeting so many people who have fought through an oppressive mental health system, who have been forcibly electroshocked and drugged, who have been treated as less than human--and who are now leading accomplished and fulfilling lives as authors, directors of organizations, social activists, etc., has been inspiring and empowering. I just hope that eventually the general public will hear our stories and take them as their own."

### **Born:**

13 August 1973

**Contact info:** Worcester, Massachusetts, USA [www.freedom-center.org](http://www.freedom-center.org)

**Currently doing:** In addition to being a participant, Oryx is Director of the MindFreedom Oral History project. He co-founded the Freedom Center in Northampton, the Pioneer Valley's only support/activist group run by and for people labeled "mentally ill" (see [www.freedom-center.org](http://www.freedom-center.org)). At his "day job," he works to support consumer-run businesses, connecting people with meaningful work opportunities. He is also an avid basketball player, golfer, hiker, and writer.

**Mental health experience:** Inpatient, Outpatient, Psychiatric Drugs, Coercive Treatment

**Psychiatric labels:** Bipolar

**Psychiatric drugs taken in the past:** Depakote, Risperdal, Zyprexa, Klonopin

**Off psychiatric drugs since:**

2002

**Recovery methods:** Self-Help, Family/Friends, Literature, Social Activism, Spirituality, Diet, Exercise, On good therapist, Peer Support, Art/Music, Regulating sleep, Yoga, Tai Chi, Meditation

**Greatest obstacle:** Abuse and lies both within and without the mental health system

I was lucky to be alive. When I woke up in the trauma center at UMass Memorial Hospital on September 21, 1999, I immediately realized my mistake. Of course cars can't fly.

Yet somehow, just the day before, I had convinced myself that my 1993 Acura Legend would accelerate through the slow moving van in front of me and take off into the air, landing me in the waiting arms of a lady friend several continents away.

As I talk about this now, I wonder how this could happen. I had always been a "responsible" person: a 3.96 student at Lewis & Clark College, an administrator for the "I Have a Dream" Foundation, a graduate student on full scholarship at the University of Massachusetts. "Logic," it seemed, had always exuded from my pores.

It still amazes me how fast you can lose touch with physical reality. The days leading up to the accident were some of the most interesting/manic/crazy/spiritual days of my life. I was meeting new friends, speaking up in class like I never had before, attending lectures, and going to parties. The stress of moving 3000 miles away from home, from Oregon to Massachusetts, and being in a totally new environment, amplified every emotion I felt during those weeks.

It was much more than I was used to, but before long I felt like I could do anything. I could charm any woman, out debate anybody on any topic, conquer any obstacle. Even my perceptions were improved. The sky seemed a more brilliant blue, the trees were more magnificent, everything was so unbelievably, heart-achingly beautiful. I thought I had figured it out. I thought I was enlightened.

Naturally, I wanted to share what I had found with everybody I came across. So I became a preacher. I talked non-stop about philosophy and the secrets of life. I wrote down what I felt were the key universal truths, and was set on sharing what I had found with others. I felt that people were trapped in their own minds, their own fears, and didn't recognize that they were connected with everybody and everything.

I wanted to create a revolution of the mind. I distributed flyers and tried to organize underground meetings. I was going to change the world and nothing was going to stop me. I decided to quit school and write a book about my enlightening experience.

It was on the car ride home that I went beyond the point of no return.

At a stoplight, it felt so good to throw my road map and spare change--everything that was not a necessity--out the window. In the span of a few seconds, I convinced myself that the rules of physical reality existed because we believe they exist. I convinced myself that my car could fly. And until I woke up in that hospital, I believed I was going to make it to my destination.

When my mother told a psychiatrist that I thought I could fly the car, I was transferred from the trauma center to the psychiatric ward as soon as I could walk. It was with visions of electroshock and lobotomy that I "voluntarily" checked in to the ward on the 8th floor of UMass Memorial Hospital.

I was interviewed by a few "lower level" staff and finally a psychiatrist came in and told me what I "had." She gave me a diagnosis of bipolar disorder and told me I would probably be on psychotropic drugs for the rest of my life.

She didn't ask me anything about my life prior to my week of mania; it was as if that didn't matter. To them, I was just another diagnosis. I could never be "cured," but medications could help "stabilize" me so I could manage my emotions.

I was in the psychiatric ward for six days, but it felt like a month. They expected me to take psychiatric drugs, even though four years of studying psychology as an undergraduate had ingrained a fear of their damaging side effects deep within me. I was terrified of the medications: I knew all about tardive dyskinesia, and the thought of my facial muscles twitching involuntarily haunted me.

But after awhile, I could see that my concerns would not be heard. "Time to get your meds!" Soon I was a part of the twice daily "round-up" to receive my doses of Risperdal, a powerful neuroleptic, and Depakote, a "mood stabilizer." Nobody was excused from the round-up. One day, I noticed a rather innocent clock behind the nurse on duty. In huge letters it had written across it: "RISPERDAL." It was then that I truly realized the extent of the drug companies' domain.

There were other programs: various support groups, art therapy, occupational therapy. These programs were better, but there was always the focus on medication. The best part was the bonding and friendship with the other patients. We were all in the same boat and we supported each other immensely. We had too.

In fairness, most of the staff was incredibly well meaning, but I felt that they were victims of an oppressive system as well. I always felt distanced from my supposed caretakers, like an impenetrable wall divided the patients from the staff, the "weirdos" from the "humans."

By the end of my stay, the psychiatrists had upped my dose to 2000 MG of Depakote per day. I was told that this was a low to moderate dosage. Basically, I was duped.

After I returned home, I got severely nauseous a few times a week, vomiting up everything I ate. At first I thought it was bad pizza, only to soon realize that it was the Depakote. I was actually on an extremely high dosage. Not only did it make me physically ill, the Depakote made me extremely tired and lethargic, and affected my concentration as well. Soon I was sleeping over 10 hours a night and still feeling tired during the day. At times, my hands would physically shake because my body was simply overwhelmed by this noxious chemical. Because Depakote increases your appetite, I also gained 20 pounds in the span of two months.

Finally, after talking with five psychiatrists, at the University of Massachusetts I finally found one who treated me like a person. He immediately recognized that I was severely over-medicated. Even though it was his job to discuss "medication management," he seemed more interested in getting to know who I was.

When I woke up in that hospital bed, I knew I was going to recover. But it didn't happen over night. I had a lot to process and many battles to face. I was lucky that I had a supportive family, a brother, mother, father, stepmother, and grandfather who each had open minds when I challenged the medical model. In fact, I would have gone off of the "medications" sooner, but I realized how important it was for me to do this with my family's support. And at first my family trusted the doctors 100%.

I was also lucky to have friends with whom I could discuss anything and who accepted me for who I am.

Perhaps most importantly, I left the hospital with a sense of urgency and purpose. I wanted to dedicate my life to creating a more progressive mental health system so that people wouldn't have to go through what I went through and what countless others have experienced.

Although it was difficult for me to deal with at times, I dove straight into the literature and started talking to other psychiatric survivors so I could learn more about what happened to me. In the process, I ran into like-minded individuals representing organizations such as the National Empowerment Center and Support Coalition International. Now all these "radical" ideas I had floating in my head were supported and reaffirmed. I can't overemphasize how important this was.

Perhaps the most difficult part of my recovery was returning to graduate school. I felt embarrassed to face people again after what had happened. Honestly, for awhile, every day was a struggle. However, I stuck it out, and those years were some of the most rewarding years of my life. I now have an MPA and, more importantly, met an incredible woman and my future wife.

Working with the Oral History Project has been incredible. Meeting so many people who have fought through an oppressive mental health system, who have been forcibly electroshocked and drugged, who have been

treated as less than human--and who are now leading accomplished and fulfilling lives as authors, directors of organizations, social activists, etc., has been inspiring and empowering. It inspired me to co-found the Freedom Center in Northampton, which is another story all in itself. I just hope that eventually the general public will hear our stories and take them as their own.

Interviewer's Comments: Oryx has an incredible amount of enthusiasm and optimism for the success of this project and the ability to change the mental health system in general. His determination inspires a hope in me that with every story gathered the psychiatric survivor movement will move closer to our goal of being heard. With Oryx's story alone, we can see that the system must change. Let's all be the momentum for that change.

**Year told:**

2001

## Activity 2.7: Exercise

Consider your own life and sense of empowerment. Fill in the table below.

Life Domain	How Much I'm in Control of this Area, Rated 1-5	Things that limit my having the control I'd like in this area
<b>Work Life</b>		
<b>Home Life</b>		
<b>Family Life</b>		
<b>Social Life</b>		
<b>Health</b>		
<b>Wellbeing</b>		

What did you learn about yourself from this exercise? Were you surprised to learn how much control you've taken in your own life in some areas? Are there areas that you wish you had more control over? Does the path toward greater control seem clear? Doable? We'll come back to this as we work with other topics in the class.

## Unit 3: Journey to Self-Help & Inner Wisdom Trainer Notes

### *Unit Goals and Objectives:*

- Understand concepts of Inner Wisdom & Self-Help
- Identify 3 reasons why inner wisdom in personal health, including mental health, is important
- Identify 3 self-help practices that support mental wellness.
- Identify 3 personal strategies that support inner wisdom

### *Summary of Main Ideas:*

- Tapping into and trusting inner wisdom is a critical path in a recovery journey
- We can't support others to trust their inner wisdom if we have not tapped into our own inner wisdom.
- We are the experts on ourselves

### *Materials*

- Workbook
- Laptop and projector
- Screen
- Flip chart paper (preferably ones that stick to the wall)
- Markers (various colors)
- Pens (one for each student)
- Snacks
- Toys
- Name tags or tents

### *Preparation:*

- Review Video 3: Inner Wisdom
- Be fully familiar with the material prior to the class so you can answer questions and/or facilitate classroom conversations

## Unit 3

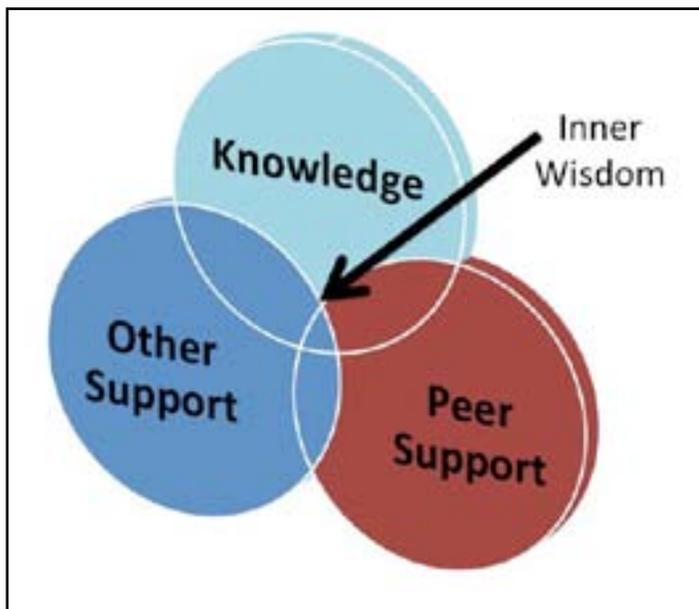
Activity 3.1	Exercise
Activity 3.2	Video
Activity 3.3	Reading
Activity 3.4	Exercise
Activity 3.5	Video
Activity 3.6	Exercise



### Journey to Self-Help and Inner Wisdom

In the last section, we talked about the road of hope and empowerment. Empowerment is about gaining confidence in one's own capacity to make decisions and have control over one's life. It is fundamental to personal recovery.

Closely related to “empowerment” is the concept of “inner wisdom.” “Inner wisdom” is knowledge from within that guides us to our own answers and solutions. While “empowerment” says, “I have the right to choose,” “inner wisdom” say, “and my choice is....” Empowerment and Inner Wisdom exist side-by-side, but also support each other to be stronger. Inner Wisdom gives direction for empowerment, and empowerment allows inner wisdom to become realized in the world. Inner wisdom combined with empowerment leads us to look both inside and outside the box for our questions and our answers.



Inner wisdom is key to peer work. Throughout the history of the consumer-survivor-expatient (c/s/x) peer movement, inner wisdom has led people to say “No” to ‘treatment as usual’ when something inside told them it was anywhere from unhelpful to abusive.

Inner wisdom has led people to question the unquestionable opinions of people “in the know” and people in power. Inner wisdom has led people to create meaningful supplements and alternatives to the “status quo.” Let’s look at some examples:

Jean-Baptiste Pussin was a patient in Bicêtre Hospital in the mid-1700's. After discharge, he chose to stay and work at the hospital, eventually becoming superintendent. Unlike the "treatment as usual," his inner wisdom from personal experience was that kindness rather than cruelty, meaningful work activity rather than boredom, and hope instead of hopelessness are far more effective in supporting recovery. His student, Pinel, known as the "father of psychiatry," spread this practice worldwide. It became known as "moral treatment" and was very effective. Budgetary cuts, overcrowding and staff shortages shifted the system away from moral treatment to custodial care.

Elisabeth Packard, a minister's wife and mother of several children, had the audacity to express different religious beliefs than her husband. The laws of the time allowed her husband to institutionalize her. During her three years of fighting for her freedom, he left with the children and all their belongings. Once discharged, he denied her access to her children due to her documented "insanity." Her inner wisdom said that this was wrong, despite the beliefs of the day and the force of the law. She fought to be declared "sane" (and prevailed) in a court case against her husband, (Packard v. Packard). Her actions resulted in changes in the law so people could not be institutionalized based on the word of family members.

Clifford Beers was hospitalized in the early 1900's. He was hospitalized for many years, and personally endured and observed many of the horrendous conditions of the day. He did a great deal of his own healing after discharge, and then wrote a seminal book, "A Mind That Found Itself." It told the story of his own emotional turmoil, the conditions within the institutions, and his own road to wellness. It also called for dramatic changes in the mental health service system. His advocacy would lead to the formation of the Office of Mental Hygiene, now known as Mental Health America.

Bill Wilson, a “hopeless alcoholic” was told by his treating specialist (addiction) that he would either die from active alcoholism or be institutionalized due to alcohol-related brain damage. Inner wisdom, however, led Bill to seek spiritual solace and guidance, leading to what he called a “spiritual awakening.” That voice from within also told him that he could only keep it by sharing the message to others. This was the birth of Alcoholics Anonymous, the first peer-run self-help group that is now world-wide.

In the 1980’s, Mary Ellen Copeland was in the depths of emotional distress. Her one thread to meaningful activity was a research project for school. The project involved interviewing people about things they used or did to cope with their “symptoms.” As she was gathering the information, her inner wisdom led her to try out different strategies that others were using. Over time, she saw that many of these strategies were totally changing the quality of her life. In her enthusiasm, she told her doctor that she was going to publish a book with these strategies as a self-help tool for people. Despite her doctor’s opinion that she was delusional, she went on to create the Wellness Recovery Action Plan (WRAP),<sup>1</sup> a self-help tool that’s used all over the world.

Charlie Carr was in a diving accident when he was 15 and sustained a spinal cord injury. As a paraplegic, he was required to finish high school and college from hospital beds that, to him, were like prisons. He knew he was delegated to this prison for the rest of his life. His inner wisdom said that it wasn’t right to be forced to live in hospitals. With others in the country, he fought for the right to live in the community. His work led to laws requiring curb cuts, accessible buildings, and personal assistants. He was also part of creating the Boston and Northeast Centers for Independent Living. He is now the Commissioner of the Massachusetts Rehabilitation Commission.

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1 *Mental Health Recovery and WRAP*, copyright ME Copeland.

Today, we can't imagine a husband having the authority to institutionalize a wife, a world with no AA or WRAP, or people with spinal cord injuries living their entire life in a hospital because buildings and sidewalks aren't accessible. But at the time, very few could imagine anything different. People in authority and power, like doctors and legislators, said so and most dutifully agreed. "Conventional wisdom" - an acceptance about something because of familiarity - 'so it *has been*, so it *shall be...*' - takes over and dulls our sense of interest and curiosity about whether or not the practice is helpful and valuable or harmful. Believing only in the "status quo" also leads us to accept that what we have now is all that there is, even if what we're offered leaves us feeling hopeless and defeated in life.

Inner wisdom, on the other hand, involves being in touch with a discomfort inside that leads to curiosity, questioning, evaluating and brainstorming possible other alternatives.

### **Exercise 3.1 Reflective Exercise**

1. Let's go exploring about... "Inner Wisdom"

*The exercise is a quick word-association game. Just write down the very first thing that comes to mind. And if nothing comes to mind, then nothing is the right answer.. Have fun with this and don't 'deep think' it...*

- a) What words come to mind?
  
- b) What images come to mind?
  
- c) What tools come to mind?
  
- d) What songs comes to mind?

e) How does it feel - physical? emotional? other?

f) What skills come to mind?

g) What colors comes to mind?

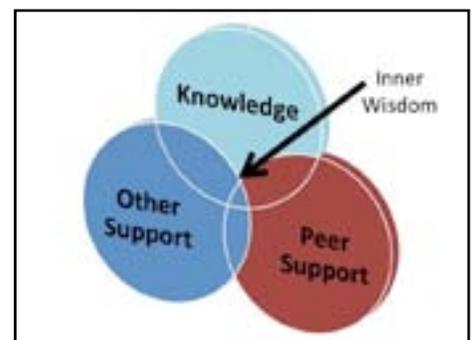
h) What people come to mind?

i) What strength come to mind?

2) How has your own inner wisdom guided you in your recovery?

For many of us, it's hard to be in touch with and trust our own inner wisdom. Like empowerment, inner wisdom is impacted by many factors, like environment, medications, support, etc. It's also harder to tap into inner wisdom when we're not exposed to others who have some of the knowledge and information that we can work from.

Let's consider some of the factors that can support our ability to tap into and trust our inner wisdom. The first is simply experiencing the process of checking within ourselves and tapping into resources created through others' inner wisdom:



- \* Do I feel as good as I'd like to feel?
- \* Am I in control of as much of my life, including levels of emotional distress (symptoms) as I'd like to be?
- \* Are there other things out there that I can try? (Experiment)
- \* Which of these works for me?

This is the type of process that is outlined in Mary Ellen Copeland's Mental Health Wellness and WRAP program.

### 3.2 Video: Mental Health Matters: Wellness Recovery Action Plans

<http://youtu.be/LdZ4bmwY9G4>

### 3.3 Reading: Wellness Recovery Action Plans

## ***WELLNESS RECOVERY ACTION PLAN***

**A system for monitoring, reducing and eliminating  
uncomfortable or dangerous physical symptoms  
and emotional feelings**

*developed by*

**Mary Ellen Copeland, MS, MA**

**Author of**

*The Depression Workbook:  
A Guide to Living with Depression and Manic Depression*

*Living Without Depression and Manic Depression:  
A Guide to Maintaining Mood Stability*

*Winning Against Relapse:  
A Workbook of Action Plans for Reoccurring Health and Emotional Problems*

*The Adolescent Depression Workbook*

*The Worry Control Workbook*

# WRAP - Wellness Recovery Action Plan

By Mary Ellen Copeland, MA, MS

WRAP is a self-designed plan for staying well and for helping you to feel better when you are not feeling well to increase personal responsibility and improving your quality of life.

The first part of WRAP is developing a personal Wellness Toolbox. This is a list of resources you can use to develop your WRAP. It includes things like contacting friends and supporters, peer counseling, focusing exercises, relaxation and stress reduction exercises, journaling, creative, fun and affirming activity, exercise, diet, light, and getting a good night's sleep.

Section 1 of WRAP is the **Daily Maintenance Plan**. It includes three parts: 1.) a description of yourself when you are well, 2.) those Wellness Tools you know you must use every day to maintain your wellness, and 3.) a list of things you might need on any day.

Section 2 is identifying those events or **Triggers** that, if they happened, might make you feel worse--like an argument with a friend or getting a big bill. Then, using Wellness Tools, you develop an action plan you can use to get through this difficult time .

Section 3 is identifying **Early Warning Signs**, those subtle signs that let you know you are beginning to feel worse, like being unable to sleep or feelings of nervousness. Then, again, using your Wellness Toolbox, developing an action plan for responding to these signs you feel better quickly and prevent a possible difficult time.

Section 4 is **When Things are Breaking Down**. In this section, you list those signs that let you know you are feeling much worse, like you are feeling very sad all the time or are hearing voices. And again, using your Wellness Toolbox, develop a powerful action plan that you that will help you feel better as quickly as possible and prevent an even more difficult time.

Section 5 is a **Crisis Plan** or **Advance Directive**. In the crisis plan, you identify those signs that let others know they need to take over responsibility for your care and decision making, who you want to take over for you and support you through this time, health care information, a plan for staying at home through this time, things others can do that would help and things they might choose to do that would not be helpful. This kind of proactive advanced planning keeps you in control even when it seems like things are out of control.

Section 6 is the **Post Crisis Plan**. You may want to think about this part of the plan in advance and even write some things to do in that time. However, you may want to write most of it as you are beginning to recover from the crisis—when you have a clearer picture of what you need to do for yourself to get well.

Review your plans every day, noting how you feel and doing what you need to do to help yourself get better or to keep yourself well. . As you become familiar with your plan, you will find that the review process takes less time and that you will know how to respond without even referring to the book. People who are using these plans regularly and updating them as necessary are finding that they have fewer difficult times, and that when they do have a hard time it is not as bad as it used to be and it doesn't last as long.

The WRAP approach empowers you to take control of your own health and wellness. Since its development, the system has been shared with thousands of people through the [books](#) Wellness Recovery Action Plan, Winning Against Relapse, the Winning Against Relapse Audio Tape, the Creating Wellness Video series, numerous support groups, workshops and seminars, and through the [www.mentalhealthrecovery.com](http://www.mentalhealthrecovery.com) web site.

### **Symptoms Monitoring and Response System**

Through careful observation you will learn: the things you need to do every day to keep yourself well, external events that may trigger an increase in symptoms, early warning signs of an impending episode, and symptoms that indicate you are in trouble. With this knowledge, and by using the tools listed here, and others you have discovered for yourself, you will be able to develop a symptoms monitoring and response system (Wellness Recovery Action Plan™) that will help you keep your moods stabilized. This system would include listings of:

- those things you need to do every day to keep yourself well, such as eating three healthy meals and getting a half-hour of exercise
- external events that could trigger symptoms, such as an argument with a friend or getting a big bill, and responses that might keep this event from causing or worsening symptoms
- early warning signs - such as irritability or anxiety - that indicate your symptoms may be worsening, and a response plan
- symptoms that indicate the situation is getting much worse, such as reckless behavior or isolation, and an action plan to stabilize the situation

### **Wellness Toolbox**

Use the following tools as part of your symptoms monitoring and response system to reduce symptoms and maintain wellness.

1. talk to a supportive person
2. attend a support group
3. talk to your counselor, doctor or other health care professional
4. peer counsel - share talking and listening time with a friend
5. structured focusing exercises
6. relaxation and stress reduction exercises
7. fun, affirming, creative activities
8. journaling
9. daily planning
10. exercise
11. light exposure
12. dietary improvement - avoiding caffeine, sugar and heavily salted foods
13. increasing or decreasing the stimulation in your environment
14. stop, analyze the situation and make a thoughtful decision on how to proceed

### **Crisis Planning**

Write a personal crisis plan to be used when your symptoms have become so severe and/or dangerous that you need others to take over responsibility for your care. Your crisis plan includes:

- a list of your supporters, their roles in your life, and their phone numbers
- a list of all medications you are using and information on why they are being used
- symptoms that indicate you need your supporters to make decisions for you and take over responsibility for your care
- instructions that tell your supporters what you want them to do

Give completed copies of your plan to your supporters so they have easy access to it when necessary. Update your plan as necessary.

## **Addressing Traumatic Issues**

If you feel your symptoms are caused or worsened by traumatic events in your past, seek out a treatment program that:

- validates your experiences
- empowers you to take positive action in your own behalf
- helps you establish connection with other people

## **Suicide Prevention**

Up to 15% of people diagnosed with depression or manic depression end their lives by suicide. Make sure that doesn't happen to you by:

- treating symptoms early
- setting up a system with others so you are never alone when you are deeply depressed or out of control
- having regularly scheduled health care appointments and keeping them
- throwing away all old medications and having firearms locked away where you do not have access to them
- keeping pictures of your favorite people in clear view at all times
- instructing a close supporter to take away your credit cards, check books and car keys when you are suicidal
- always having something planned to look forward to

## **Developing a Wellness Lifestyle**

Develop a lifestyle that supports your wellness by:

- using self-help books to improve your self-esteem and change negative thoughts into positive ones.
- enhancing your life with pets, music, and activities that make you feel good
- having a comfortable living space where you feel safe and happy
- establishing a career or avocation that you enjoy
- keeping your life calm and peaceful
- taking good care of yourself
- managing your time and energy well
- spending time with people who are positive, affirming and fun

## **Conclusion**

Because of the discouraging nature of these illnesses, and because it may take a long time before we realize the results of our efforts, many of us find it very difficult to motivate ourselves to work on our recovery. Learning and sharing information in a workshop has the substantial benefit of increasing participants' sense of belonging and hope and gives them the support they need to work on their own recovery and/or assist others as they move through the recovery process.

### 3.4 Exercise: Mental Health Recovery, 5 Key Concepts

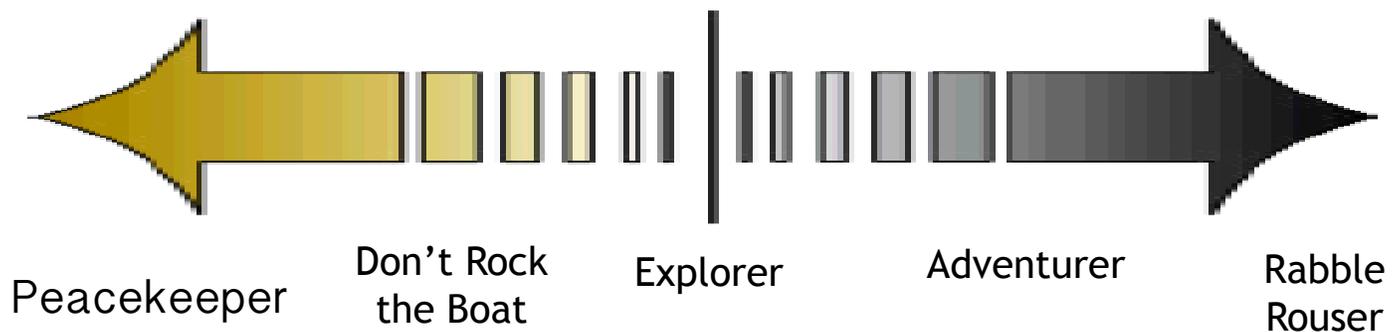
*Mental Health Recovery and WRAP were built around 5 key concepts. For each of the 5 concepts, list things in your own life that you do to promote your own wellness.*

<b>Key Concept</b>	<b>How It's Reflected In Your Own Life</b>
<i>1. Hope - helps you see yourself as an agent for positive change in your life.</i>	
<i>2. Personal responsibility - being proactive and using your freedom and power to move in the direction you want in life.</i>	
<i>3. Education - learning all you can about yourself so you can make good decisions about your mental health and your life.</i>	
<i>4. Self-advocacy - being able to speak up for yourself and expressing yourself clearly and calmly.</i>	
<i>5. Support - developing and keeping a strong support system.</i>	

Practices like WRAP and other self-help tools help us to become the experts on ourselves through self-exploration, trial and error, and self-knowledge. Not everything will fit well, but by trying different things, we become more aware of who we are, what we need, what we want and how to make it happen for ourselves.

There are many other self-help approaches, some which people do primarily on their own and some which are group based. We'll talk about a number of them later in the training, and there's a list of peer-run self-help programs in the appendix section of this manual.

As we continue to explore different approaches, it's important to check-in with ourselves to see how comfortable we are going outside of mainstream thinking. When conflict arises, do you find that you jump in and try to make everyone happy to make the conflict go away, or at least, make sure you're not the one rocking the boat? Do you feel more comfortable following paths already laid out by others, or do you like to be a little more adventurous, taking different pieces of information to reach your own roadway, whether or not it stays in step with most people. Or, finally, do you find that you actually really like stirring things up, challenging people to rethink what they believe? There's no right or wrong answer to this question, although you may find at some point that being a peer worker is more challenging if you're a peacekeeper or someone who'd rather not rock the boat. We'll get to this later, but in the meantime, just look at the bar below and indicate where you see yourself on the scale.



Another thing we see from the stories of people like Bill W and Mary Ellen Copeland is that their curiosity, questioning and creativity led to “out of the box” solutions to difficulties that many were experiencing. While most people didn’t necessarily set out to create alternative solutions, their willingness to continue the journey “outside the box” once they began to realize that they might be on to something is important.

## In the Box and Out of the Box



We’ve talked a lot about “in the box” and “out of the box” thinking. Let’s talk a little more about each of these and their importance to recovery and peer work

“in the box” approaches to healing center around what’s known as the “medical model.”

The term “medical model” refers to a set of procedures that all doctors, including psychiatrists, are trained to follow when evaluating and treating “illnesses” and injuries, almost as if the human body were a machine.<sup>1</sup> The step-wise process is:

1. Listen to person’s general complaint
2. Take or get a “History” of the illness or injury - what’s happened before
3. Physical Exam - External examination of the physical body
4. Get any needed tests (to get info from inside the body that can’t be seen on the outside)
5. Based on the physical exam and test results, render a diagnosis.
6. Based on the diagnosis, prescribe treatment and offer prognosis

So, let’s say I fall down and land on my wrist. I go to the hospital and tell the doctor that my arm hurts alot. She asks me what happened and I tell her that I was

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1 Ronald D. Laing in his *The Politics of the Family and Other Essays* (1971),

playing soccer and fell, landing on my arm (history.) She looks at my arm and sees that its all red and swollen and is very warm. (Physical exam). She suspect that my arm is broken and sends me to get an x-ray (extra tests). The x-ray shows a fracture, so she tells me that I have to have a cast put on my arm (treatment), but that it's a nice clean fracture and should heal well (prognosis). Pretty straight forward & seems to make sense, except.....



What does the psychiatrist observe during the physical exam???? (Look sad? Bouncing leg?)

What x-ray, blood test, CAT Scan guides the doctor to know what's going on within our body???

So, as we see, the usual objective scientific method of the “medical model” is lost when it’s applied to emotional distress. Unfortunately, as it’s presented as coming from “medicine” and “doctors,” people tend to believe that we actually know a lot more than we do.

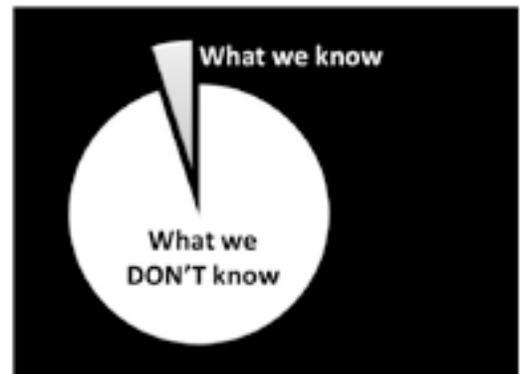
Here’s what the U.S. National Institute of Health tells us about the cause of what are called “severe mental disorders.”



Research has been carried out into what factors make people more vulnerable to developing Schizophrenia. Brain chemistry, genetics, birth complications and social factors such as an urban upbringing, migration and adversity have all been considered. Recently, a strong link has been established between the use of strong cannabis and the development of schizophrenia. There are no compelling reasons to favor one cause over another, and current scientific opinion suggests that it is caused by a mix of factors.

## The Big Take-Aways from “In the Box” Thinking

- We know a lot less than most people think we know
- the power of the pharmaceutical companies, etc. keep the medical model perspective in front and equally valid alternative understandings of emotional distress in the background (like trauma, environmental, and social factors)
- The medical model’s focus on illness and intervention (i.e. medication) are, in and of themselves, spirit breakers, hindering peoples’ chances of seeing and believing in recovery for themselves and others.



Are we saying that the medical model is wrong, that there is no biological components of emotional distress and that medication is never a good treatment? Not at all. That’s always an individual decision that should come out of informed decision making - decision making after having all the information needed.

What we are saying, though, is that it’s equally wrong to be given information as if it is a fact, when it’s not. This is especially true when the information is dismal and leads to hopelessness. Telling someone who is being diagnosed with schizophrenia that it is a lifelong brain disorder and that people will, at best, get stabilized with life long medication that will likely cause all sorts of other physical illnesses is harmful, and therefore not “help.” We are saying that when people are told they must “comply” for their own good, or be forced to comply, even when the facts don’t support that the treatment is going to help someone is also wrong. These are the issues that we think about as we think about “in the box” and “out fo the box” approaches.



## “Out of the Box” Thinking

Out of the Box thinking is about attitudes and actions.

“Attitudes” is about reframing who we are, what we’re allowed to do, and taking and speaking truth to power. For reasons

that we don’t have to go into, the mental health system is one with great power over people. Once somehow has a diagnosis, his or her credibility and capability can be forever questioned. One word from a psychiatrist can deny someone their liberty, or force them to take drugs with known adverse side-effects or ECT treatments that electify the brain without any good science behind what it does or doesn’t do to the brain cells.

Knowing that we can speak up, can question and challenge and ultimately make our own decisions is the change in attitude that goes along with ‘out of the box’ thinking. You may fully agree with the recommendations from your physician, but only after an active role in gathering the information needed to make an informed choice.

Actions related to ‘out of the box’ thinking include learning about and evaluating non-medical models of understanding emotional distress as well as self-help approaches to wellness.

Self-help is particularly important because it supports us to look beyond the beliefs that only medicine can impact how we feel, leaving us at the mercy of “luck.” Self-help, on the other hand, shows us where we do have control, and for many, provides alternatives that are as effective or more effective than pharmaceutical interventions.

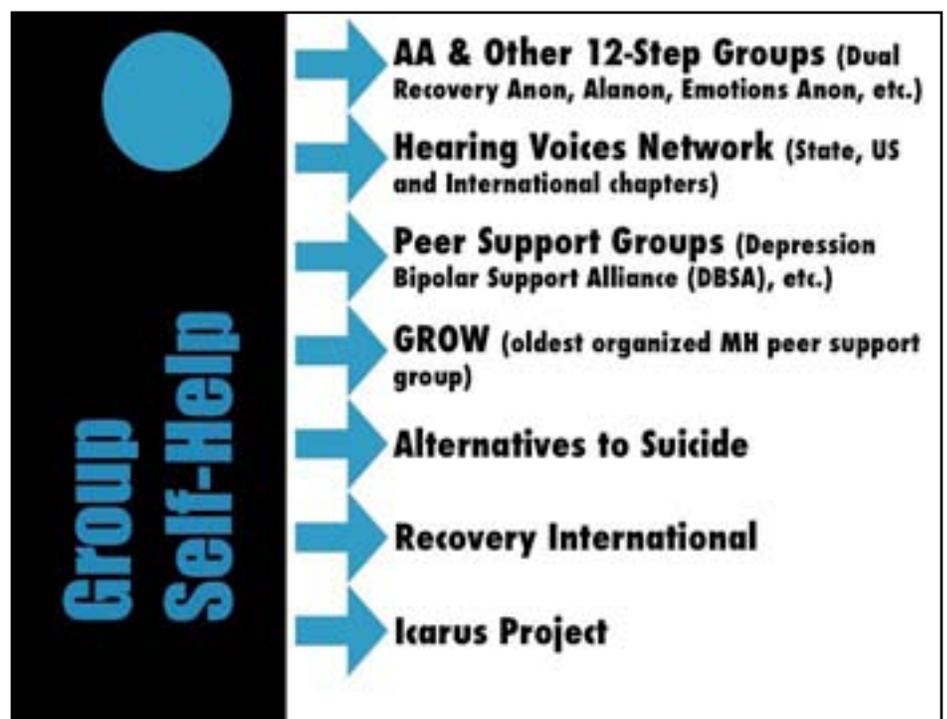


What is your experience with any of the items in this list? Do you know these approaches? Have you used any of these? Have you used them on your own and not part of a treatment plan or something offered as part of a program requirement?

## Self- Help: Self Helping Self

Self paced, self-determined, can choose to do or not do each day, no permission needed, so not in treatment plans, personal decisions about involvement, level of involvement and if its meaningful or not meaningful at all times.

What is your experience with any of the items in this list? The Western Mass. RLC has been a leader in bringing several of these to the state.



### 3.5 Exercise: Self Help Self-Assessment

Complete the table below. For each self-help resource, indicate the best answer: you are *AWARE* of the resource (but don't know much about it), *KNOW ABOUT* the purpose of the resource, have used the resource or want to learn more about it.

Self-Help Resource	AWARE	KNOW ABOUT	USED	WANT to LEARN MORE
WRAP				
Pathways to Recovery				
Madness Network				
The Icarus Project				
12-Step Groups				
Hearing Voices Network				
Alternatives to Suicide				
Depression and Bipolar Support Alliance (DBSA)				
Recovery Learning Communities				
Recovery Centers (Substance Abuse)				
The Freedom Center				
Peer Support Groups				
PhotoVoice				
BU CPR Recovery Center				
Afiya Peer Run Respite				
Groundhogs				
M-Power				

### 3.6 Activity: Get to know your community

*This is a multi-part exercise. It's meant to give you the opportunity to explore the community and reflect on how different resources can be useful to inspire hope, provide education, support personal responsibility, empower self-advocacy or offer support. This activity is self-paced. It's more important to do some meaningful exploration than "complete" the exercise.*

*Assignment:*

- 1) Go to at least two Recovery Learning Communities. (If you're involved in one already, go to a second one)*
- 2) Go to one Recovery Center*
- 3) Go to the Freedom Center*
- 4) Research one of the two following resources: Madness Network or Icarus Project*
- 5) Research or attend one of the following: Hearing Voices Network, Alternatives to Suicide or DBSA.*
- 6) Research Afiya and the Recovery Center at BU Center for Psychiatric Rehabilitation.*

<b>Resources</b>	<b>Useful For You</b>	<b>Useful In General</b>
RLC 1		
RLC 2		
Recovery Center		
Freedom Center		
Madness Network/Icarus		

Continued....

Resource	Useful For You	Useful In General
Hearing Voices Network, Alternatives to Suicide, or DBSA		
AFIYA		
BU Center for Psych Rehabilitation		

What **similarities** did you notice in these different resources?

What **differences** did you notice in these different resources?

What “*out of the box*” approaches did you see?

What did you see that can support people to discover their own inner wisdom?

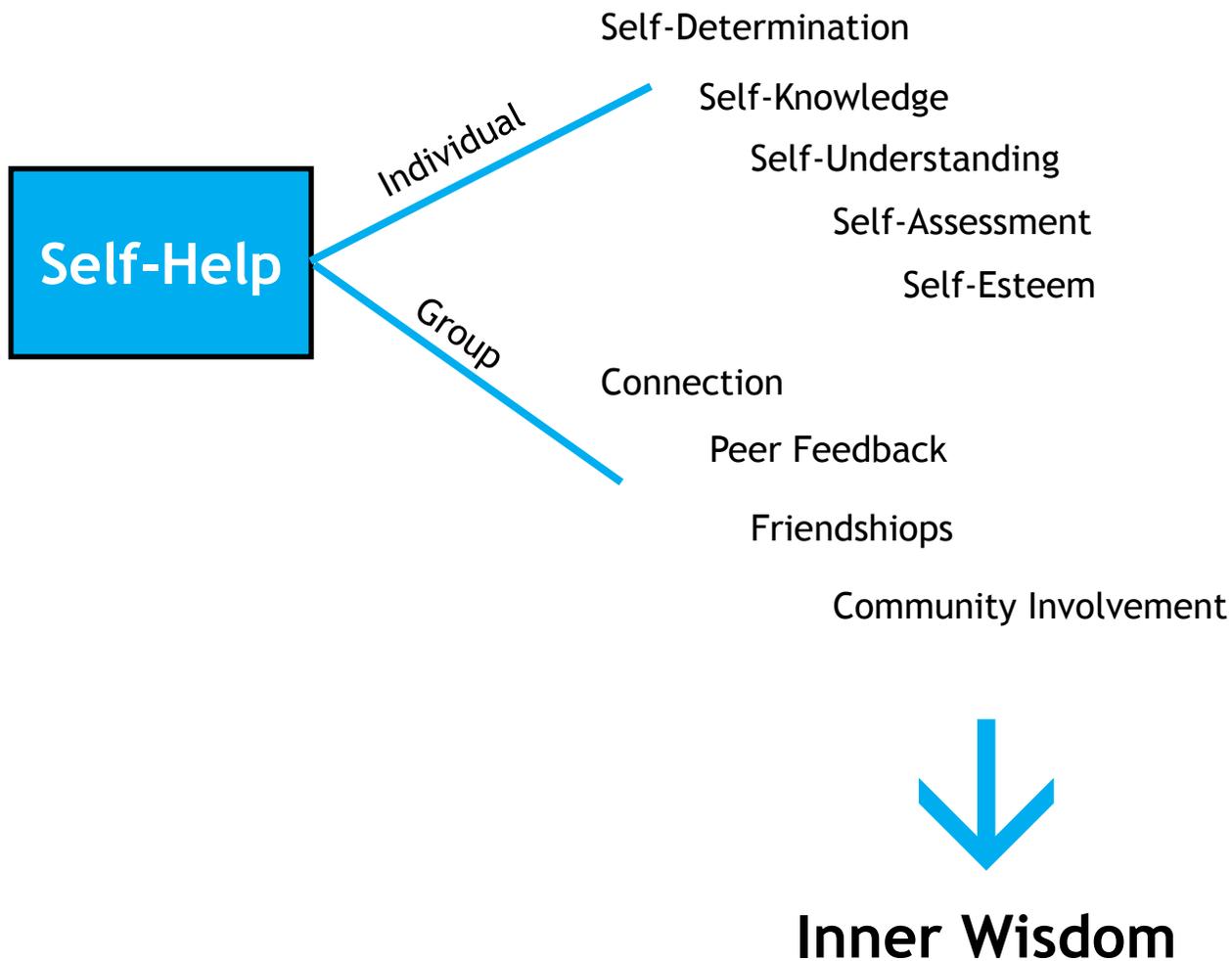
What stood out for you as you explored these different resources?

How do you see these in relation to traditional services?

What other questions do you have?

How can you get answers to these questions?

# The Link between Self-Help and Inner Wisdom



Self-Help, on our own and with others, is an ideal avenue to move beyond the limitations of being a passive recipient of treatment and victim of an internal process over which we have no control. The exploration leads to self-assessment, self-knowledge and self-determination. These, in turn, are the elements that support our inner wisdom, and our ability to voice it.

## Unit 4: Journey to Healing: Redefining Help Trainer Notes

### *Unit Goals and Objectives:*

- Recognize that “help” can be helpful or not helpful
- Identify 3 unintended consequences of “doing for” people
- Identify 3 core philosophies of a redefined helping framework

### *Summary of Main Ideas:*

- Peer work relies on a helping framework based on mutuality and relationship
- Traditional help models disempower people and lead to dependence on the system
- Helping requires us to remember that each of us is the experts on ourselves
- As peer support workers, our job is always to support people to discover their own inner wisdom

### *Materials*

- Workbook
- Laptop and projector
- Screen
- Flip chart paper (preferably ones that stick to the wall)
- Markers (various colors)
- Pens (one for each student)
- Snacks
- Toys
- Name tags or tents

### *Preparation:*

- Review Video 4: Redefining Help
- Be fully familiar with the materials and exercises prior to the class so you can answer questions and/or facilitate classroom conversations

### Unit 4

Activity 4.1	Video
Activity 4.2	Exercise
Activity 4.3	Reading
Activity 4.4	Exercise
Activity 4.5	Reading
Activity 4.6	Video
Activity 4.7	Exercise



## Journey to Healing: Redefining Help

*H*elp is a concept deeply woven into the fiber of the mental health system. Everyone working in the system is working in a “helping” profession. We often utilize services because we’ve asked for “help.” Family and others hope we get the “help” we need, and society fears us when we’re not getting the appropriate “help.” It’s a system that circulates around “help.”

But what is *Help*? What “help” have you received? Have you received “help” that didn’t feel so helpful? What kind of things have you done to be helpful to others? Do you know if the person felt like you had been helpful? Have you ever offered what seemed to be something helpful that ended up to be a disaster?

Our healing journeys are supported or hindered, in part, by the quality of “help” we get, so it’s important that we really think about this idea of “help” so we have some guidelines for ourselves and for supporting others.

Take a moment to jot down your experiences with “help.”

**Help I’ve received:**

**Help I’ve given:**



## 4.1 Video: Redefining Help

Trainer Note: The table below should be completed and discussed before looking at the answer sheet on the following page. You should have reviewed the answers before facilitating the discussion.

### 4.2 Exercise:

*The video described the importance of shifting how we think about “help.” The questions below are for your own reflections about “help” in your life and as you consider being a peer support worker.*

What is the inherent message that is given when someone “does for” you?

What are the risks associated with a relationship in which helping means that one person “does for” the other?

Describe an experience in which someone was trying to help but you didn’t feel it was helpful:

What would have been more helpful? How would you have defined help?

*Consider the following scenarios from the perspective of the traditional approach to helping. Then, rethink how to approach this from a peer relationship orientation.*

Traditional Professional Helping Relationship	Peer Relationship
Help is defined by the person's diagnosis, behaviors and symptoms and the goal of "help" is to reduce maladaptive behaviors, increase functioning, and to stabilize and maintain symptoms.	
Helping someone means to protect the person from making bad decisions and suffering negative consequence.	
To help the client means to tell them what they should and should not do in order to prevent relapse.	
Pointing out when the client makes mistakes is using poor judgment, or is not thinking clearly is to be helpful.	
Taking medications and going to therapy is the course of treatment that is typically helpful.	
Providing oversight and monitoring to ensure compliance is part of the helping relationship.	

Possible Answers:

Traditional Professional Helping Relationship	Peer Relationship
Help is defined by the person's diagnosis, behaviors and symptoms and the goal of "help" is to reduce maladaptive behaviors, increase functioning, and to stabilize and maintain symptoms.	All help should be person-driven, not system driven. The goal of help should be to support the person do and be what the person wants.
Helping someone means to protect the person from making bad decisions and suffering negative consequence.	Everyone learns through trial and error, taking calculated risks, etc. Denying someone this right takes away the opportunity to move forward.
To help the client means to tell them what they should and should not do in order to prevent relapse.	No one knows the future, so whether something will or won't lead to relapse is anyone's guess. Plus, relapse is part of recovery. We all experience stress when we take risks and make changes in life.
It is helpful to point out when the client makes mistakes. is using poor judgment, or is not thinking clearly.	It is helpful to support people to self-assess what they can learn from any situation to gather more information to use for the future.
Taking medications and going to therapy is the course of treatment that is typically helpful.	There is so little known about how medications work and the long-term consequences that it's always important to weight and balance all the options on a regular basis rather than just agreeing with the doctor.
Providing oversight and monitoring to ensure compliance is part of the helping relationship.	Non-compliance is often the first sign that someone is taking back their own life and is something to be applauded and embraced.

The video also discussed the ideas of language. Language reflects how we think. Consider that not too long ago, people who used wheelchairs were called “invalids,” people that were in-valid. That term reflected how people viewed people using wheelchairs. Somehow, if the person couldn’t walk, they were seen as also unable to think, feel, have dreams and aspirations, or thrive in a meaningful, full life. As the community demanded that people use different language, people also began to view people with disabilities in a different way.

It’s the same thing within the mental health recovery movement. People will continue to fear us, see us as unstable, and discriminate against us unless we start using different language and demand that others do so as well.

More important, using different language can help us see ourselves differently. The term “mental illness” came out of efforts of state hospital superintendents who wanted to be seen as “reputable” and part of the medical community. The medicalization of emotional distress wasn’t based on science, and even now, the science of “mental illness” is pretty small. The U.S. National Institutes of Health (NIH) explains that scientists believe that “major mental illnesses” are caused by some unknown combination of genetics, involving a combination of genes that aren’t yet understood, biology, environment, social and economic conditions. In other words, they don’t really know very much yet. At the same time, it’s been well-established that poverty impacts health, and trauma impacts physical and emotional wellbeing. So, in the end, we know a little and we don’t know a lot. BUT....

Here are some things that most people **incorrectly think we know**:

- Emotional distress, especially emotional states labeled Schizophrenia, Bipolar and Major Depression are caused by a chemical imbalance;
- PET scans and other scientific methods have identified what parts of the brain and nerve circuitry that cause different “mental illnesses”
- Medications were created to target the part of the brain identified as causing the emotional distress. For example, anti-depressant medications target the part of the brain and chemicals of the brain known to cause depression.

- “Mental Illnesses” are life-long chronic illnesses
- People with mental illnesses are violent

These, of course, are all myths. We know that recovery happens on a regular basis, regardless of diagnosis. We also know that people have found many roads to recovery, many of them not involving regular treatment and/or medications.

### 4.3: Reading

#### *You and Me by Debbie Sesula*

If you're overly excited, You're Happy  
 If I'm overly excited, I'm manic  
 If you imagine the phone ringing, You're stressed out  
 If I imagine the phone ringing, I'm psychotic  
 If you're crying and sleeping all day, You're sad and need time out.  
 If I'm crying and sleeping all day, I'm depressed and need to get up.  
 If you're afraid to leave your house at night, You're cautious.  
 If I'm afraid to leave my house at night, I'm paranoid.  
 If you speak your mind and express your opinions, You're assertive  
 If I speak my mind and express my opinions, I'm aggressive  
 If you don't like something and mention it, You're being honest.  
 If I don't like something and mention it, I'm being difficult.  
 If you get angry, You're considered upset.  
 If I get angry, I'm considered dangerous.  
 If you over-react to something, You're sensitive  
 If I over-react to something, I'm out of control  
 If you don't want to be around others, You're taking care of yourself  
 If I don't want to be around others, I'm isolating myself and avoiding  
 If you talk to strangers, You're being friendly  
 If I talk to strangers, I'm being inappropriate.

**For all the above, you're not told to take a pill or are hospitalized  
 But I am !**

It's up to us to begin to change language so people using services, providing services and people in the community as a whole can begin to learn more truths and dismiss the myths. Let's look at some examples of how a simple shift from the way we usually say things to a non-clinical human experience descriptive term can make a difference.

## 4.4: Exercise

Medical Model, Deficit Based Language	Human Experience Language	How does this seem different to you?
Sally is a schizophrenic	Sally has periods of time when she experiences hearing voices and altered states.	
People with mental illness need to have better access to treatment	People experiencing emotional distress should have a wide array of options that they can easily access, understand and choose between.	
People with severe and persistent mental illness deserve the same insurance benefits as those with physical illnesses.	Insurance should be equal for people experiencing physical or emotional distress.	
Marcus is a Borderline.	Marcus has been diagnosed with Borderline Personality Disorder.	
Jose is Bipolar and has periods of time when he's real manic.	Jose has a diagnosed with Bipolar Disorder. At times, he experiences periods of high energy and a real good mood, but uses meditation, nutrition and other tools to keep things from going too far.	
Tanisha is low-functioning. Recovery doesn't apply to people like her.	Tanisha has been significantly impacted by her diagnosis, treatment and loss of hope and meaning. It may take more intense exposure to recovery for her to begin to believe that it might be possible for her.	

## 4.5: Reading

# Recovery Language

**Words have power. They have the power to teach, the power to wound, the power to shape the way people think, feel, and act toward others.**

∞ Otto Wahl

Our language reflects our beliefs and the way we view people. We are often unaware of the impact that the words we choose can have on our own attitude as well as on those around us.

The way we speak to and about people is a window into what we are really thinking. Communication is a highly complex thing. With the words we choose we can convey the fact that we truly value people, that we believe in them, and that we genuinely respect them. Or, the words we choose can make it clear that we do not.

People living with mental illness tend to be put down, discouraged, demoralized, and marginalized. We can either reinforce that with the language that we choose or we can fight it.

None of us should be defined by our problems or diagnoses, or by a single aspect of who we are; we are people first and foremost.

### Consider this...

**DON'T portray successful persons with mental illness as superhumans.** This carries the assumption that it is rare for people with mental illness to do great things. It is also patronizing to those who make various achievements.

**DON'T sensationalize a mental illness.** This means not using terms such as “afflicted with,” “suffers from,” “victim of,” and so on.

**DO put people first, not their labels.** Say, for example, “person with schizophrenia” rather than “schizophrenic.”

**DO emphasize abilities, not limitations.** Terms that are condescending must be avoided.

**DO focus on what is strong instead of what is wrong**

**What should we call people?  
What's the best label to use?**



**How about not  
using labels at all!**

**The most respectful way to refer to people is as people.  
Whenever possible, use the person's name.**

# Samples of Recovery Language

The following are some of the terms that we have traditionally used to describe people and/or their behaviors. These terms place judgment and blame on the individual and generalize their actions. It is much more helpful to describe the specific situation that a person is facing than to use generic and punitive clinical terms

<b>Worn Out Language</b>	<b>Language that Promotes Acceptance, Respect &amp; Uniqueness</b>	<b>Comments</b>
Max is mentally ill  Max is schizophrenic  Max is a bipolar  Max is...	Max has a mental illness  Max has schizophrenia  Max has been diagnosed with bipolar disorder  Max is a person with...	Avoid equating the person's identity with a diagnosis. Max is a person first and foremost, and he also happens to have bipolar disorder  Very often there is no need to mention a diagnosis at all  It is sometimes helpful to use the term "a person diagnosed with," because it shifts the responsibility for the diagnosis to the person making it, leaving the individual the freedom to accept it or not
Alex is an addict	Alex is addicted to alcohol	Put the person first
Rebecca is brain injured/damaged	Alex is in recovery from drug addiction  Rebecca has a brain injury	Avoid defining the person by their struggles  Put the person first
Jane is disabled/handicapped	Jane is a person with a disability	Avoid defining the person by their struggles  Put the person first  Avoid defining the person by their struggles

Mark is normal/healthy	Mark is someone without a disability	Referring to people without disabilities as normal or healthy infers that people with disabilities are not normal and not healthy
Sarah is decompensating	Sarah is having a rough time Sarah is experiencing...	Describe what it looks like uniquely to that individual—that information is more useful than a generalization  Avoid sensationalizing a setback into something huge Take the blame out of the statement
Mathew is manipulative	Mathew is trying really hard to get his needs met Mathew may need to work on more effective ways of getting his needs met	Recognize that the person is trying to get a need met the best way they know how
Kyle is non-compliant	Kyle is choosing not to... Kyle would rather... Kyle is looking for other options	Describe what it looks like uniquely to that individual—that information is more useful than a generalization  Does Kyle even agree with the plan you've developed?
Megan is very compliant	Megan is excited about the plan we've developed Megan is working hard towards the goals she has set	Being compliant means that someone is doing what they were asked or told to do. The goal of recovery-oriented services is to help the person define what they want to do and work towards it together.  Someone being compliant does not mean that they are on the road to recovery, only that they are following directions.
Mary is resistant to treatment	Mary chooses not to... Mary prefers not to... Mary is unsure about... Allie is really good at...	Describe what it looks like uniquely to that individual—that information is more useful than a generalization  Remove the blame from the statement
Allie is high functioning		Describe what it looks like uniquely to that individual—that information is more useful

			than a generalization
Jesse is low functioning	<p>Jesse has a tough time taking care of himself</p> <p>Jesse has a tough time learning new things</p> <p>Jesse is still early in his recovery journey</p>	<p>Describe what it looks like uniquely to that individual—that information is more useful than a generalization</p> <p>Avoid defining the entire person negatively based on the fact that he struggles in some areas</p>	<p>Describe what it looks like uniquely to that individual—that information is more useful than a generalization</p>
Michael is dangerous	<p>Michael tends to become violent when he is upset</p> <p>Michael sometimes strikes out at people when he is hearing voices</p>	<p>Remove the judgment from the statement</p>	<p>Remove the judgment from the statement</p>
Harry is mentally ill chemically abusing (MICA)	<p>Harry is a person with co-occurring mental health and substance use/abuse problems.</p>	<p>Avoid defining the person by the behavior</p> <p>Put the person first</p>	<p>Avoid defining the person by the behavior</p> <p>Put the person first</p>
Sam is unmotivated	<p>Sam doesn't seem inspired to go back to work</p> <p>Sam is not in an environment that inspires him</p> <p>Sam is working on finding his motivation</p> <p>Sam has not yet found anything that sparks his motivation</p>	<p>Avoid defining the person by their struggles</p> <p>Describe what it looks like uniquely to that individual—that information is more useful than a generalization</p> <p>Avoid defining the person by the behavior</p> <p>Remove the blame from the statement</p>	<p>Describe what it looks like uniquely to that individual—that information is more useful than a generalization</p> <p>Avoid defining the person by the behavior</p> <p>Remove the blame from the statement</p>
Andy is manic	<p>Andy has a lot of energy right now</p> <p>Andy hasn't slept in three days</p>		<p>Describe what it looks like uniquely to that individual—that information is more useful than a generalization</p>
Kate is paranoid	<p>Kate is experiencing a lot of fear</p>		<p>Avoid defining the person by the behavior</p> <p>Describe what it looks like uniquely to that individual—that information is more useful than a generalization</p>

	Kate is worried that her neighbors want to hurt her	than a generalization
Hailey is a cutter	Hailey expresses emotional pain through self-harm Hailey hurts herself when she is upset	Avoid defining the person by the behavior Avoid defining the person by the behavior Recognize the reason behind the behavior
Jordan has a chronic/persistent mental illness	Jordan has been working towards recovery for a long time Jordan has experienced depression for many years	Avoid conveying a prognosis It is difficult to accurately predict an individual's prognosis and it only impedes their progress to define them as someone who will not recover (or will not recover for a very long time) There is no need to address prognosis in describing a group of people or an individual
Tom is very difficult	Tom and I aren't quite on the same page It is challenging for me to work with Tom	Avoid making a judgment, which may be based on your dissatisfaction with the fact that the person has not met your expectations (which may be different from what he wants for himself)
Manipulative Grandiose In denial Passive aggressive Self defeating Oppositional	These are often people's ineffective attempts to reclaim some shred of power while being treated in a system that often tries to control them. The person is trying to get their needs met, or has a perception different from the staff, or has an opinion of self not shared by others. And these efforts are not effectively bringing them to the result they want.	These are labels for strategies and perceptions we all have about ourselves, although possibly more subtle and effective. We all present information to achieve a desired result to some degree (manipulation). Or have an inflated opinion of ourselves, or are unable to see or agree with something presented to us by another.



## Unit 5: Journey to Reflection Trainer Notes

### *Unit Goals and Objectives:*

- Recognize how reflecting on our journeys prepares us to share our stories
- Identify at three parts of our journey that are important to reflect upon
- Identify three or four turning points in our own journey

### *Summary of Main Ideas:*

- Peer support is founded on sharing experience to inspire hope, model recovery, and share tools and strategies.
- Hindsight gives us clarity on what our experiences were and were not and what lessons we bring with us.
- If our experiences are too raw to explore, they're not available to us in our work supporting another.

### *Materials*

- Workbook
- Laptop and projector
- Screen
- Flip chart paper (preferably ones that stick to the wall)
- Markers (various colors)
- Pens (one for each student)
- Snacks
- Toys
- Name tags or tents

### *P*reparation:

- Review Video 4: Redefining Help
- Be fully familiar with the materials and exercises prior to the class so you can answer questions and/or facilitate classroom conversations

### Unit 5

Activity 5.1    Exercise  
Activity 5.2    Videos



## Journey to Reflection

Peer support rests on the foundation of sharing our own lived experience of being diagnosed with, treated for, and finding our way beyond a psychiatric label. Some of us may find value in the diagnosis, but have moved beyond living our diagnosis. Others of us may have rejected the label, seeing ourselves as surviving and thriving from trauma or other combinations of social, economic and environmental factors.

As we begin to think about sharing our experience with others as part of being a peer worker, we want to spend some time reflecting on what our experience(s) has looked like, what we've learned, what helped along the way, and how we can share this to be helpful for others.

In the Certified Peer Specialist class, we talk about the difference between an "Illness" story and a "Recovery Story."

An illness story talks about:

- My diagnosis
- My medications
- Bad things that have happened - 'war stories'
- Hopelessness
- An ongoing belief that my diagnosis rules who I am and who I can be

Let's look at an illness story.

"I'm Lyn. I was diagnosed with mental illness when I was 17, when I was in a state hospital. I've spent most of my life in the hospital, some of them being the most horrific places. I remember when I was in Mass Mental, and it was really overcrowded and we had to sleep on mattresses on the floor. At night, men would crawl into bed with me. It was horrible, especially for a trauma survivor. And this is really what my life was like - restraints, quiet rooms, hospitals....until my doctor



3. What strengths and talents have you discovered/rediscovered that enhances your healing journey.

4. What tools or self-help have you used to support your journey.

5. How can you summarize your difficult times in a way to let listeners know that you've "been there, done that" without getting mired down in the "war stories."

6. What is your message of hope - your own unique message from your own journey?

## 5.2: Videos

Follow the links below to a series of short recovery story videos. After each video, complete the following reflective questions.

Liz

<https://www.facebook.com/photo.php?v=492017896190&set=vb.142359255814299&type=2&theater>

1. How did you feel at the end of the story? Did you feel a sense of hope?
2. If yes, why? If not, why not?
3. What stood out to you in this story?
4. Was this a recovery story or an illness story?

Linford

<http://youtu.be/N1dW8PdvfvQ>

1. How did you feel at the end of the story? Did you feel a sense of hope?

2. If yes, why? If not, why not?

3. What stood out to you in this story?

4. Was this a recovery story or an illness story?

Amy

<http://www.youtube.com/watch?v=e-S5-yS3uTMr>

1. How did you feel at the end of the story? Did you feel a sense of hope?

2. If yes, why? If not, why not?

3. What stood out to you in this story?

4. Was this a recovery story or an illness story?

Peter

<http://www.youtube.com/watch?v=3Flhk67O-Yw>

1. How did you feel at the end of the story? Did you feel a sense of hope?
2. If yes, why? If not, why not?
3. What stood out to you in this story?
4. Was this a recovery story or an illness story?

Pat

<http://www.youtube.com/watch?v=ymoucNmm7v0>

1. How did you feel at the end of the story? Did you feel a sense of hope?
2. If yes, why? If not, why not?
3. What stood out to you in this story?
4. Was this a recovery story or an illness story?

We can see from these examples that recovery stories can be very different from each other, but still have commonalities - inspiring hope and talking about strategies and people that support recovery.

### **5.3: Exercise**

*Go back to Exercise 5.1. Would you add or subtract anything based on the recovery stories that you heard?*

If you are currently working, you have, of course, had the opportunity to use your recovery story. If you haven't had the experience, just sharing snippets here and there is a good beginning to feeling comfortable disclosing your story to others... Some other quick things you may want to keep in mind if you're just beginning to disclose your story:

- Be mindful of who your audience is. What we might share with another person in recovery vs. a colleague vs. a family member may be very different.
- We can share parts of our story for a variety of purposes in addition to inspiring hope, such as educating people about services (from the user perspective), feeling hope and hopelessness, things that helped, etc.
- We want to stay away from graphic details about past events, especially those that be difficult for the listeners to hear. The purpose of telling our stories is to offer something to another person or people. If people get triggered by what we're saying, though, they tune out for self-protection. This means they're not hearing anything we're saying anymore, so we've defeated our purpose.
- Similarly, we want to make sure that we don't say disclose more than we're comfortable with. We're allowed to have privacy and decide what we want to share and what we'd rather keep private.























