TAKE YOUR HEART TO WORK

Advanced Assignment

Developed 2008 **Revised 2015**
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Integrate what you believe into every single area of your life.
Take your heart to work, and ask the most and best of everybody else, too.
Don't let that get beaten down.

Meryl Streep, "At the Heart of a Champion"

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INTRODUCTION AND INSTRUCTIONS

Note to Participants: Because of time constraints, **you will need to complete this assignment prior to the training.** The information in this Advanced Assignment (Take Your Heart to Work Peer Support Specialist Participant Manual, Section I, Parts One – Seven, Personal Recovery is a State of Mind and Section ll, Part Twelve, History of Mental Health) needs to be submitted to the Facilitator of the Take Your Heart to Work: Peer Support Certification Training class that you are participating in, **at least one (1) week prior to the first day of class.** This is the prerequisite online assignment that was listed on the application. There are 23 questions highlighted in yellow. Some questions require written answers, some require reading and understanding and your opinion. This Advanced Assignment will be reviewed, but will not be graded, so please do your best, and do not worry about a grade. Copying other people's work is unacceptable. However, your active participation in class is required and is also based on the Advanced Assignment.

Please answer on a separate document using question and page numbers for clarity. You do not have to copy this document.

Assessment for understanding the definitions and concepts will be covered within the 50 hour face to face training. The questions are listed below, and additional information can be found on the page numbers listed.

ASSIGNMENT QUESTIONS

Goals, Mission, Vision, Expectations for Participants, & Graduation Requirements:

1. p. 6-7: Goals, Mission, Vision, Expectations for Participants, & Graduation Requirements – Read and understand. Put your thoughts in writing and be prepared to actively participate in the group discussion.

Section I, Parts One – Seven:

2. p. 7-9: Research the meaning of peer support and find 2-3 perspectives. Write a report sighting the authors and references. Examples: Shery Mead, Mary Ellen Copeland, and Pat Deegan, and Peer Support Websites including www.pss.unc.edu, bhs.unc.edu, maryellencopelandphd.com, etc.

3. p. 7-9: Develop your own perspective ideas on the meaning of peer support and how you believe it is different from therapy and other health care.

Section I – Advanced Assignment (Continued)

4. p. 7-9: Based on your findings, give an example that demonstrates you have received peer support. Was it helpful or harmful? Explain.

5. p. 7-9: Based on your findings, give an example that demonstrates you have given peer support. Describe your experiences.

6. p. 9-11: Introduction to Self-Care – Read and understand. Be prepared to actively participate in the group discussion. Put your thoughts in writing.

7. p. 9-11: Self-monitoring Summary – Add your thoughts to items 1-3 and write down your answers.

8. Review and update your personal WRAP.

9. p. 11-14: Code of Conduct, Ethics & Values Introduction – Be very familiar with the Code of Ethics (North Carolina Certified Peer Support Specialist (NCCPSS) on p. 11-12. Know this acronym and become familiar with the website www.pss.unc.edu.

10. p. 15-20: Core Values of PSS – Read and understand. Be prepared to actively participate in group discussion. Put your thoughts in writing.

11. p. 20-23: Boundaries – Write and know the definition of boundaries, violations, and troubleshooting tools.

12. p. 23-27: Positive Role Model – Read introduction of Recovery Values and answer in writing the eleven (11) questions on these pages.

13. p. 24-25: Recovery Environment – How can you develop this with the person served?

14. p. 25-27: Define stigma and write two (2) ways you, as a PSS, can reduce stigma in your community.

15. p. 27-28: Qualities of an Effective PSS – Be familiar with the qualities and identify those that will be difficult for you to embrace. Put your thoughts in writing.

Section II – Advanced Assignment (Continued)

Section II, Part Twelve:

16. p. 28-66: History of Mental Health – Read and focus on the Early History of Mental Health; Dorothea Dix; Deinstitutionalization; Community Based Crisis Intervention; History of the Peer Movement; Historical Events; Nothing About Us Without Us; Support, Recognition and Disability Pride; How Do We Know Recovery Works?; and Mental Health Reform in the United States and in North Carolina, including the legislative actions taken. Put your thoughts in writing and be prepared to actively participate in the group discussion.

17. p. 29 & p. 63: Answer in writing the four (4) questions on each of these pages.

18. p. 30-36: Read about the "The Lives They Left Behind." Put your thoughts in writing and be prepared to actively participate in the group discussion.

19. p. 39-66: Create a timeline citing the history of recovery.

Section IV, Part Four:

20. p. 66-69: Providing Peer Support When Working with an Agency – Read and understand. Put your thoughts in writing and be prepared to actively participate in the group discussion.

Videos – Review and Summarize

21. p. 69: Review the videos on the Take Your Heart to Work – Peer Support Playlist (found here – on YouTube: https://bit.ly/TYHW-PeerSupportVideos) *Note: Some of these videos deal with serious and possibly difficult topics. List at least three (3) things from each video that stood out to you.

Articles – Review and Summarize

22. p. 69-81: Review the articles included with this assignment. Read and understand. Put your thoughts in writing and be prepared to actively participate in the group discussion. List at least three (3) things from each article that stood out to you.

Advanced Assignment (Continued)

Community Resources

23. p. 81: Identify and research three (3) resources that are available in your community. Gather information (website, brochure, flyer, etc.) and be prepared to share these resources with the class.

GOAL

The goal of the TAKE YOUR HEART TO WORK Training Program is to empower participants to use critical thinking skills and to provide them with emerging Best-Practice Peer Support Specialist training within a caring, Recovery orientation.

MISSION

The mission of the TAKE YOUR HEART TO WORK Training Program is to develop professional, marketable skills for and by people in recovery by focusing on a conceptual foundation with practical application.

VISION

The TAKE YOUR HEART TO WORK Training Program will establish a "thinking with your heart" structure based on a strengths-first program, which empowers people in Recovery to become mutually supportive with their peers in making informed choices and moving toward the life they want and deserve, rather than relying on impersonal systems. We meet people where they are on their journey.

EXPECTATIONS FOR PARTICIPANTS

- Graduation from a 20 hour Wellness Recovery Action Plan® (WRAP), NAMI Peer to Peer, or Whole Health Action Management (WHAM) 20 hour training or another accredited wellness plan.
- Certification is granted from Behavioral Health Springboard, UNC Chapel Hill, School of Social Work and does not guarantee employment.

- GED or high school graduation is not a requirement for this training, but it is for NC Credentialing from the Behavioral Health Springboard, UNC Chapel Hill, and may be for employment with some agencies.

- A Comfort Agreement by and for participants creates a necessary safe learning zone. We all serve as "trust facilitators."*

- Attendance and Active Participation are required for completion of this curriculum. Any absence or tardiness will require attendance in another face to face training to make up the time and the information missed.

- Class preparation is necessary for participants to comprehend all aspects of the material and to demonstrate understanding. Advance research and comprehension are required.

- **Refund Policy:** The Training Fee of $375.00 is due 2 weeks prior to the first day of the training. Please make out the check or money order to the information you receive from your Monroe Consulting, LLC Trainer**.** You will receive a receipt the first day of training, if not before. We will make every reasonable effort to support you to graduate from this training. In the event of your inability to attend or reschedule, you will receive a refund upon request. Non-refundable amounts include $100.00 Administrative fee, and fees for the days you did attend.

Appropriate accommodations necessary to complete curriculum requirements will be provided for all participants upon request.

***Trust Facilitators** – People who maintain a level of trust as it relates to topics on the Comfort Agreement.

1. p. 6-7: Goals, Mission, Vision, Expectations for Participants, & Graduation Requirements – Read and understand. Put your thoughts in writing and be prepared to actively participate in the group discussion.

Section I, Part One: What is Peer Support?

INTRODUCTION to RECOVERY

To understand Peer Support and be effective Peer Support Specialists, we must understand the concept of recovery. Personal recovery is a state of mind. It is how we think about things. It can also be said that recovery is the way we live – our lifestyle. It is a way of doing, being, and living. According to Heather Masson, of the Canadian

Mental Health Association, "Persons suffering from mental or physical illness must not define themselves by their illness, but rather the unique individual that they are. Any illness may make your journey through life more challenging, however, recovery is possible for anyone. Recovery is a process in which an individual suffering with mental illness acquires insight into their strengths and abilities, and continues to work toward meaningful goals despite residual symptoms of their illness. Success is not measured by others, but rather by the person themselves."

Recovery includes the process of developing, restoring, discovering, or rediscovering, a sense of personal positive, and meaningful identity separate from a person's diagnosis, illness, disability, symptoms, addiction, condition, or even behavioral history. Recovery involves building a rich and meaningful, and satisfying life, as defined by the person themselves, whether or not there are ongoing or recurring symptoms or problems, diagnosis, condition, history, or presumed limitations. The process of recovery also involves a process of growth and transformation as the person moves beyond the acute (short term) distress often associated with a mental health challenge or illness, and develops newfound strengths, and new ways of being. As Peer Support Specialists, it is our job to support people by meeting them where they are, engaging with them, and empowering them as they walk along their recovery journey.

Recovery is closely associated with social inclusion and being able to take on meaningful and satisfying roles within local communities, rather than in segregated services. Recovery is the process of working trough the challenges in life that we all experience, and coming out a stronger person.

PEER SUPPORT

Peer Support is lots of things, as you can imagine. This section is just the tip of the iceberg when it comes to explaining and describing everything that makes up Peer Support. This introduction and will help to establish a working definition and general understanding of Peer Support.

Peer support has been described as "Social emotional support, often with instrumental support, mutually offered or provided by persons having a mental health struggle, to others sharing a similar condition to bring about a desired social or personal change" (Solomon, 2004). Peer Support can be beneficial for people who share all sorts of conditions, from mental health struggles (i.e. depression, anxiety, etc.), to physical health challenges (i.e. cancer, diabetes, Down Syndrome, etc.), to emotional challenges (i.e. grieving the loss of loved ones), to (people who live under similar conditions (i.e. caregivers for people who have special needs), to addiction (i.e. alcohol and/or drug use, gambling, etc.).

The Canadian Mental Health Association describes Peer Support as "People with similar lived experiences giving each other encouragement, hope, assistance, guidance, and understanding that aids in recovery. It can be done anytime or anywhere when two or more peers are in a mutual, supportive relationship."

Peer Support is built on the three key principles of respect, shared responsibility, and the mutual agreement of what is helpful.

Sherry Mead explains peer support in this way:

> "Peer support is not like clinical support, nor is it just about being friends. Unlike clinical help, we don't really think of each other as sick and in need of constant professional help, but instead, we understand each other because we've "been there," shared similar experiences and can model for each other a willingness to connect. In peer support, we come together with the intention of changing our patterns, getting out of stuck places, building relationships that are respectful, mutually responsible, and potentially mutually transforming."

The Copeland Center for Wellness and Recovery describes Peer Support and Recovery in the following manner, "Developing or restoring a positive and meaningful identity apart from one's diagnosis, symptoms, condition, even behavioral history. It is about building a rich, meaningful, and satisfying life despite one's diagnosis, symptoms, condition, history, or presumed limitations."

1. p. 7-9: Research the meaning of peer support and find 2-3 perspectives. Write a report sighting the authors and references. Examples: Shery Mead, Mary Ellen Copeland, and Pat Deegan, and Peer Support Websites including www.pss.unc.edu, bhs.unc.edu, maryellencopelandphd.com, etc.

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Section I, Part Two: Taking Care of Yourself

Building on the Five Key Concepts Plus Two of WRAP (Wellness Recovery Action Plan) developed by Mary Ellen Copeland, we have come to understand the importance of commitment to our own personal recovery strategies by systematically monitoring our own wellness. This includes knowing ourselves and our own personal limits, specifically (and especially) when it comes to our wellness. Our own issues with wellness may compromise our ability to be effective in our positions, so we will notify others around us (such our supervisors, sponsors, and/or other supporters), when we are experiencing “signs” of moving away from recovery. The sooner we address what is happening, the greater likelihood we have of returning to our wellness. At all times, we will prioritize personal support, wellness, and Recovery. “Practice what you preach!” Let’s talk:

> Those of us who are Wellness Educators have found that we are often able, and very naturally, to focus on supporting others’ wellness while putting our own on the back burner. <u>As a Peer Support Specialist (PSS), it is our personal responsibility to take the steps necessary to keep ourselves well</u>. We can inadvertently find ourselves slipping into “When Things are Breaking Down” before we realize it, often times denying it until we are in a full blown crisis. The recovery process is different for everyone. Each of us is on our own unique journey. We do know from WRAP that people who are the most successful in recovery need to have Hope, Personal Responsibility, Education, Self-Advocacy, Support, Medication Management (if necessary) and attention to Physical Health. We need to make sure that we take care of ourselves, so that we are able to mentally and physically be the best Peer Support Specialist we can possibly be. We need to do things to renew and rejuvenate ourselves, because we are not very effective when there is nothing left to give – we cannot pour from an empty cup.

After having defined and updated our Wellness Recovery Action Plan (WRAP), and reviewing how we can use it to manage our wellness in all parts of our lives, now let’s look at how we are able to communicate with our supervisor and other necessary people when things are breaking down and when we may not be able to effectively support others.

Summary: So how do we assume the responsibility to monitor our own wellness?

1. One way to do that is to be “up close and personal” with our WRAP. This involves making changes as we grow and learn new ideas. By being up close and personal with our WRAP, we are demonstrating that we not only believe in the RECOVERY process but we are living it to the fullest.

2. We are also able to teach ourselves to humbly ask for help. This is a difficult thing to do when we are the Wellness Educators or the Peer Support Specialists. Our supervisor or other co-worker with whom we have a mutual relationship is an example of an individual to ask for support. Some agencies have a quality assurance process. For example, a form filled out by the employee and sealed and kept under lock and key by the supervisor. It is to be opened only in case of an emergency. The form includes emergency contact information (supporters) and a crisis plan (WRAP). This is an excellent way to be assured that your wishes are carried out even when you are not able to carry them out yourself.

3. Another way to take care of ourselves is to build relationships with the people who mean the most to us by communicating honestly and openly with them when we have issues. In peer support, we come together sharing ideas and information. It is about being mutual – being reciprocal – where both people have the same feeling(s) and type of relationship directed toward each other. It is not about giving advice. In addition to that, the concept of peer support can enrich relationships with everyone in our lives. We will talk more about effective communication in Section III, as well as making connections and mutuality in Section II, Part 3.

5. p. 9-11: Introduction to Self-Care – Read and understand. Be prepared to actively participate in the group discussion. Put your thoughts in writing.

6. p. 9-11: Self-monitoring Summary – Add your thoughts to items 1-3 and write down your answers.

7. Review and update your personal WRAP.

Section I, Part Three: Code of Conduct/Ethics

What is a Code of Conduct?

We could define a Code of Conduct as a system of rules that govern the way we are to behave. Sometimes called a Code of Ethics, it is usually included as part of the employee manual. These are guidelines for acceptable and unacceptable behavior.

For example:

1. Ensure that that the people we are supporting are not harmed or exploited in any way;

2. Protect us as Peer Support Specialists by allowing us to know up front what is expected of us (i.e., through job description)
3. Safeguard our agency by laying out the professional behavior that is expected.

It is important that we perform all of our job responsibilities in a manner that is consistent with the Code of Conduct/Ethics of the agency where we are employed. We also need to perform our jobs consistent with the NCCPSS Code of Ethics (see below). In some areas these Codes may overlap and in other areas they may be quite different.

Ethics vs. Values

One way to look at the difference between ethics and values would be to say that **values are *what you believe*** and **ethics are *how you behave*** *(or how you put your values into action).*

NCCPSS VALUES AND CODE OF ETHICS

The North Carolina Certified Peer Support Specialist (NCCPSS) Code of Ethics was developed by a workgroup consisting of North Carolina Certified Peer Support Specialists, Supervisors, and other stakeholders over a three-day meeting held in Chapel Hill, North Carolina. This code outlines uniform standards and expectations to North Carolina Certified Peer Support Specialists in the workplace. These ethical standards are intended to offer clear boundaries in the workplace for Peer Support Specialists.

Disclaimer:

The North Carolina Certified Peer Support Specialist (NCCPSS) Certification indicates the person retaining this certificate has successfully completed the requirements established by the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services. These requirements may be located on the NCCPSS website for further review. Any violation of this code of ethics should be submitted in writing to the NC Certified Peer Support Specialist Program and shall be governed by policies and procedures established within the hiring entity.

VALUES

- People have the right to be treated with dignity and have their individual human rights respected.
- Self-directed recovery does happen, with or without professional help.

- Sharing our recovery experiences fosters mutual relationships, reduces isolation, inspires hope, and strengthens the ongoing recovery process.
- Individuals have the right to live the full and meaningful lives they envision for themselves.
- People have the right to make their own choices about their treatment even if others think their decisions are wrong.
- Peer Support values the importance of community building and natural supports (family, church, NA, AA, friends, etc.).

CODE OF ETHICS

- Attention to self-recovery is critical to the performance of duties as a Peer Support specialist(s) (PSS). When changes in recovery occur, the Peer Support Specialist will take personal responsibility to seek support.
- PSS are honest in their interactions; keeping it simple, keeping it real.
- PSS relationships are mutual learning experiences.
- PSS have a responsibility to support people to use their own voices to advocate for the principles of human dignity, self- determination, and empowerment.
- PSS honor commitments made to peers. PSS strive to always explore and ask open ended questions rather than making assumptions. PSS explore alternatives and options with peers rather than giving advice.
- PSS support people to make their own choices, honoring self-determination. The PSS does not put his/her agenda ahead of the peer's agenda.
- PSS negotiate within the relationship with peers in order to facilitate peer choice and shared power.
- PSS avoid power struggles and favoritism.
- PSS will not exploit, devalue, manipulate, abuse, neglect, or ignore a peer.
- PSS and peers will not loan or borrow anything from each other; especially not money.
- PSS will not establish romantic relationships with peers and will refrain from intimate or sexual activity with peers.
- PSS avoid dual relationships; when they are unavoidable, appropriate boundaries are established within the relationship with the support of the supervisor.

- PSS will not violate a peer's confidentiality except when required by law.
- PSS does not accept or give gifts, if allowed by the agency, must be clearly related to the peer's recovery process.
- PSS do not take peers to their homes; any exception to this must have written agency approval.
- PSS do not hire peers to work for them if they are currently receiving services from their agency.
- PSS's documentation in the agency record is person-centered, strength-based and done with the peer whenever possible.
- PSS take responsibility for their own professional development and are proactive about expanding their knowledge and honing their skills with continuing education and training.
- PSS have a responsibility to educate themselves about available community resources and to establish helpful contacts in the community.
- PSS do not make medical diagnoses.

I affirm that:

☐ I have reviewed the ethical guidelines.

☐ I have not violated any of the ethical codes.

Name: ____

Signature: ____

Date: ____

As Peer Support Specialists, we need to understand and abide by the NCCPSS Values and Ethics, not only when we are reaching out to and engaging with the people we are supporting, but at all times and in all of our interactions with people. This not only helps up to build and maintain a professional peer relationship, but also empowers us to become role models of recovery and Peer Support.

8. p. 11-14: Code of Conduct, Ethics & Values Introduction – Be very familiar with the Code of Ethics (North Carolina Certified Peer Support Specialist (NCCPSS) on p. 13-14. Know this acronym and become familiar with the website www.pss.unc.edu.

Section I, Part Four: Core Values of PSS

These topics will be discussed and will hold varying degrees of power, truth and acceptance for each participant. The purpose in this exercise is to dig as deeply inside oneself as possible to achieve self-awareness by coming to terms with, understanding, and applying Peer Support Specialists' Core Values, as we reach out to, engage with, support, and empower people. This helps us to develop and build professional peer relationships.

You may find some, if not all, of the following practices and characteristics pertinent to your personal abilities as a Peer Support Specialist.

1. Recognizing that all people have rights and choices

What are some of the rights and choices that we all have? What are some of the rights and choices we (and those we support) have been denied? Why is it important to have conversations around rights and choices with the people we support? How do we help support people to self-advocate for their rights and choices? Refer to the Bill of Rights handout in your addendum.

2. Not defining differences

Is it important not to put the focus on or define differences of individuals? Explain. Why is it important to see all people as "People First"? How are we similar as people? What are the ways in which you are able to demonstrate that we, as people, are "more alike than different"?

3. Focusing on each individual's strengths and talents

Explain why it is important for us to support people in identifying their strengths and talents. Give an example of how you would support someone to explore their strengths and talents. What steps would you take to support a person to develop a wellness identity and share their strengths and talents in a practical and realistic way?

4. Recognizing multiple perspectives and truths

How do people form their perspectives? Does an understanding of cultural values serve us in a discovery and recovery process? Explain. What is one able to learn from other peoples' perspectives? Do you believe that each of us "holds a piece of the truth"? Explain. How do we give significance to someone's perception of the truth… when it is very different from our own viewpoint?

5. Defining and redefining what “help/support” and “safety” mean

Who defines “help/support” and “safety”? Can you support a person without discussing the meaning of these terms? Is “help/support” and “safety” different for each of us? Is it possible to reconcile definitions? Explain. What happens when a person does not feel safe or valued? How do we develop an environment of safety?

6. Meeting people where they are

How are open-ended questions useful upon first contact? Is it our job to give our opinion, even if we think we are right? Explain the difference in convincing someone to accept your opinion and giving informed choices to the person served.

7. Avoiding assumptions and presumptions

How can we prevent ourselves from making judgments about those we support? What may I experience when a person assumes something about me, especially when it is not factual? What do I sense when I am presumed culpable without investigation?

8. Transforming crisis to an opportunity

Share some of your experiences of when you were able to turn a crisis into an opportunity. What are we able to learn and share with others from our crises? How does this relate to being authentic? Does this relate to “telling our story”? Explain.

9. Creating self-awareness and empowerment

What are the steps you would take to learn more about your authentic self? How do we become self-aware on the inside and on the outside? See “Mobius Strip” handout. Is empowerment a result of self-awareness? Explain. Are we able to support others to become empowered or more self- aware if we are not? Explain. Is the importance of “telling our story” relevant?

10. Connecting individuals to the community

Is it important to connect people to their surrounding communities? Is isolation a factor in recovery? Explain. How and where do we connect people to their communities? Connections are about whom and what?

11. Providing goodwill in the community by modeling recovery in all settings, resulting in reduced stigma

Is it important for us to "model recovery" while off the job during our personal time (i.e. having dinner at a local restaurant, making an appointment with a person in crisis and not keeping it, storming from a community meeting)? Does our individual behavior (including when we are well, and when we may not be as well) have an impact on generic and collective stigma in the community?

12. Integrating recovery, peer support and traditional treatment

Is it possible to integrate recovery and traditional treatment? What would that look like in a social setting, detox, Mobile Crisis Unit, or Assertive Community Treatment team (ACTT)? How do we stay grounded in peer support when we are the minority in a multi-disciplinary team setting?

13. Layering networks of support that are both paid and unpaid

Give a list of potential supports that are both paid and unpaid, without expectations from either group that may do harm. How are these ideas able to become included to best serve the person at the center of the person centered plan (PCP)?

14. Adhering to the principles of trustworthiness by maintaining trust

What is trustworthiness? How do we maintain trust with those we support? Is the word "mutual" a central concept in this regard? How does mutuality relate to trust? How does trust relate to support?

15. Demonstrating commitment to personal recovery

Do you have a WRAP that works? How do you self-monitor your wellness? Are you able to naturally and freely share this part of your "story"? Explain. Do you communicate with those people who support you when you are well and when you are unwell? Describe. How do you step down from your work when you are unwell? Is it acceptable to continue working as a PSS when you are struggling? Explain.

16. Using "Person First" / "Recovery Language" to communicate sensitivity and engender mutual respect and connectivity

Do you intentionally use recovery oriented language in all settings? Are you able to use recovery oriented language in an inclusive manner? Do you view people from the perspective of having an illness identity or a wellness identity? How do you view your own identity, as an illness identity or wellness identity? Why is that important? When someone asks, "What ARE you saying?" How would you respond? How is this done effectively with whom you interact when they may prefer to use clinical terminology? What happens then to the person at the center of the Person Centered Plan (PCP) when they hear different types of language? Is consistency essential?

17. Instilling hope in order to assume personal responsibility through education and self-advocacy, thereby creating the opportunity for support

Do you believe that hope is the first step in the recovery process? How would you explain the magnitude and the meaning of the Five Key Concepts of Recovery to others? How do you feel about supporting an individual in CREATING hope? How would you support a person in establishing hope when it becomes apparent that there seems to be little hope in that person's world? Would you embrace the reality of the person served or project your own expectations… shaped from your own experiences and environment? Which Key Concept (KC) has been key to your recovery and wellness?

PERSONAL BILL of RIGHTS

1. **I have the right to ask for what I want.**
2. **I have the right to say no to requests or demands I can't meet.**
3. **I have the right to change my mind.**
4. **I have the right to make mistakes and not have to be perfect.**
5. **I have the right to follow my own values and standards.**
6. **I have the right to express all of my feelings – both positive and negative – in a manner that won’t harm others.**
7. **I have the right to say no to anything when I feel I am not ready, it is unsafe, or it violates my values.**
8. **I have the right to determine my own priorities.**
9. **I have the right *not* to be responsible for others' behavior, actions, feelings, or problems.**
10. **I have the right to expect and appreciate honesty from others.**
11. **I have the right to be angry at someone I love and express this in a responsible manner.**
12. **I have the right to be uniquely myself.**
13. **I have the right to feel scared and say "I'm afraid."**
14. **I have the right to say "I don't know."**
15. **I have the right not to give excuses or reasons for my behavior.**
16. **I have the right to make decisions based on my feelings, beliefs, and values.**
17. **I have the right to my own needs for personal space and time.**
18. **I have the right to be playful and frivolous.**
19. **I have the right to be healthy.**
20. **I have the right to be in a non-abusive environment.**
21. **I have the right to make friends and be comfortable around people.**
22. **I have the right to change and grow.**
23. **I have the right to have my needs and wants respected by others.**
24. **I have the right to be treated with dignity and respect.**
25. **I have the right to grieve in my own way.**
26. **I have the right to a fulfilling sex life.**
27. **I have the right to be happy.**

(Adapted by Mary Ellen Copeland from Edward J. Bourne, Ph.D.’s book The Anxiety and Phobia Workbook, 1990, New Harbinger Publications, Oakland, CA.)

9. p. 15-20: Core Values of PSS – Read and understand. Be prepared to actively participate in group discussion. Put your thoughts in writing.

Section I, Part Five: Boundaries (Limits)

Boundaries are ambiguous and require good judgment. We set them to protect and maintain our emotional, mental, spiritual and physical health.

They are:

- The unseen lines that you won't cross
- Undefined physical and emotional distances
- Parameters that make you unique
- Self-imposed and self-defined

The **definition of boundary** is the ability to know where you end and where another person begins. Another term for boundary is **limit.**

The amount and type of boundary (limit) responsibility you have with a person differs according to the **type of relationship**:

- **Friendship** – A person that you know, trust and one with whom you have a close personal connection – your ally, your equal
- **Colleague** – A fellow member of a profession
    - Power and authority may or may not be equal
- **Peer** (person served) – As a PSS, we have equal power with the person served and we have no authority over the person served

Boundaries are Helpful:

Boundaries facilitate relationships and protect the safe space the individuals have negotiated. Boundaries build trust and are essential to express one's authentic self. As Peer Support Specialists, we need to establish, negotiate, and maintain boundaries in order to effectively reach out to, engage with, and support people. Negotiating and establishing boundaries is a key part of developing and building professional peer relationships.

Boundary Violations:

- Any behavior or interaction which damages the relationship
- Any behavior or interaction that results in victimization
- A betrayal of the sacred covenant of trust
- Occur when Peer Support Specialists' (PSS) personal needs are met rather than the needs of the person served
- If violations occur, the ramifications may be widespread and relationships may be damaged or may be ended

Four Elements characteristically appear in Boundary Violations:

1. **Secrecy** – involves keeping critical knowledge or selectively sharing information
2. **Role reversal** – occurs when person served takes care of the PSS instead of placing the person served needs first
3. **Double-bind** – consists of messages that contradict each other while discouraging the receiver of the messages from noticing, creating a conflict of interest. It implies a threat, a sense of guilt and fear of possible abandonment by the PSS. It constricts the person served from using all available options and thus limits growth
4. **Indulgence of professional privilege** – involves using information obtained in the relationship with a person served for the benefit of the PSS. Exerting authority over the person served. <u>Having access to information does not constitute a right to obtaining it</u>.

Boundaries: Are We Helping or Hurting?

There are more gray areas than black and white ones when thinking about boundaries. PSSs can make more considerate decisions if they will take time to think about some of the basics of boundaries.

Some Warning Signs of Boundary Violations:

- Choosing sides
- Making exceptions
- Keeping secrets
- Giving or receiving gifts
- Borrowing or lending money

- Feeling as if no one but you has interest in the person served
- Feeling no one but you will be able to assist the person served
- Feeling responsible for the progress or failure of the person served
- Owning the successes or failures of the person served
- Confiding personal or professional issues or troubles about the person served to anybody

Trouble Shooting Problem Spots:

Time: When, where and how often you meet with a person served can become a troublesome issue. *<u>If it feels wrong, it probably is</u>*, but ask yourself the following questions to help clarify the situation:

1. How much time am I spending with a person served?
2. Does it vary from that spent with other persons served?
3. Am I spending “off duty” time with the person served?

Location: If a person served wants to talk or meet somewhere other than a center approved location, you may be starting to slide toward a questionable boundary as well as possible policy violation. Try asking yourself:

1. Is the location of the interaction appropriate to the relationship?
2. Would you provide peer services to other persons served at this location?
3. Is there a legitimate need to meet?
4. Have I made the meeting known to others and documented it?

Gifts: Accepting or giving a gift can get tricky. If you are unsure ask yourself:

1. Does the gift giving create a sense of obligation on the part of you or the recipient?
2. Do you do this routinely as part of your job, regardless of the age or gender of the person served?
3. Is the gift of such a personal nature that it would only be to or from specific people in certain types of (non-professional) relationships? Is there a department or center policy regarding gifts?

Asking for Help:

At all times, if you are unsure about a situation or confused about whether an interaction could be interpreted as a boundary violation, you could:

- Consult your supervisor
- Refer to the agency directives
- Consult the quality assurance coordinator
- Consult other colleagues

Adapted from South Carolina Department of Mental Health Peer Delivered Services and Minnesota Board of Nursing, January 2000

Definition of Limits:

Our personal limits are different from boundaries in that we set them for ourselves and they can change according to what kind of relationship we have with the person. The relationship may change as we get to know someone.

Adapted from Workbook for Basic Training on Peer Support developed by Stephen Pocklington

…with gratitude

10. p. 20-23: Boundaries – Write and know the definition of boundaries, violations, and troubleshooting tools.

Section I, Part Six: Positive Role Model

RECOVERY VALUES

Many of us probably had role models we respected and looked up to as we were growing up. Maybe some of your role models were family members or close friends. Maybe they were someone famous like a sports figure or musician. Maybe they were people from history who made a positive impact on the world. Maybe they were community members or religious leaders. Maybe your role models were other people altogether. One of our responsibilities as Peer Support Specialists is to continually work toward being a consistent, positive role model in whatever setting we find ourselves. We are able to model Recovery in our speech and in our actions. This involves demonstrating Recovery values. Recovery values are principles that promote recovery. This helps to break down stigma and promote community wide regard for the people we support, as well as ourselves.

The most important Recovery value we promote is **Hope**. We want to continuously express the message of hope. There is hope that people are able to get well and stay well. Hope is available to everyone. Our lives are testimony to this. Review the Key Concepts of Recovery and how each relates to the other.

Think about and answer these questions:

- What are some of your most important values?
- How have they changed over the years?
- Has being in Recovery influenced your values? In what way(s)?

We are able to reflect recovery in our attitudes, the way we feel about ourselves, other people, or situations. *There are no predetermined beliefs about anyone's recovery possibilities. A positive attitude to hold is that recovery is possible for everyone, have unconditional positive regard for them, and to view them with a wellness identity.*

Think about and answer these questions:

- Who were some of your role models while growing up? What did you admire about them?
- Who are your role models now?
- Give examples of how you could model the attitudes and actions of peer support.

RECOVERY ENVIRONMENT

It is important that we promote a Recovery Environment in our workplace, home and community. **A Recovery Environment is one in which everyone is welcome. No one is excluded. All people are valued, respected, and held in unconditional positive regard.** They are not reduced to their diagnosis or struggles. We meet them on their journeys, wherever that may be. We are not dismissive or display an attitude of giving up on somebody's recovery if they are not where "we" want them to be or make the choices we would. Instead, they are appreciated for the unique, wonderful human beings that they are. We promote empowerment and personal recovery for everyone involved – the person we are supporting, as well as ourselves. **In a Recovery Environment, emphasis is placed on how we are similar as people as opposed to how**

we are different.

Peer Support Specialists are able to promote a Recovery Environment in the workplace by intentionally making it welcoming and by using **Recovery Language** (RL). For some people, the time they spend at work each day with co-workers or people seeking services is what brings them joy and gives their lives meaning. Be aware that we are an integral part of a Recovery Environment. The way we are with others helps set the tone of the environment. Using Recovery Language is one of the easiest and most empowering things we can do to support someone.

As a Peer Support Specialist (PSS), we strive to first understand others and then work toward being understood. Stephen Covey speaks of this in his book, “The 7 Habits of Highly Effective People.” We intentionally are open and supportive to other’s ideas and focus on the positive. Being a team player is important and results in harmony, creativity, and a strong sense of ownership with feelings of connectedness.

PSSs are able to promote recovery by working to reduce stigma.

STIGMA

> *If we cannot now end our differences, at least we can help*
> *make the world safe for diversity.*
>
> *— President John F. Kennedy*

Stigma is the expression of discrimination, disapproval, judgmental attitude, or rejection toward an individual regarding personal or cultural differences, including but not limited to physical attributes or characteristics, beliefs, practices, disability, or diagnosis. Stigma is a form of ignorance that gives permission to the school yard bully, to the street gang member, and to the neighborhood gossip. Whether we are a recipient of it or a witness to it, stigma hurts us all.

As recently as August 4, 1988, a US Presidential candidate had to address rumors about his mental health. When asked whether the nominee should make his mental health records public, the opposing candidate replied, “I’m not going to pick on an invalid.”

For us as Peer Support Specialists (PSSs), stigma is not just the use of the wrong word or action. Stigma is about not respecting individual differences. It is the use of negative labels to identify a person living with issues around the topic of mental health or other challenges. Stigma is a barrier and discourages individuals and their families from getting the help they need due to the fear of being discriminated against.

There are many things that have stigma attached to them, some are physical, mental, social, or situational. Many of these stigmatized topics include abuse, especially sexual abuse, HIV/AIDS, lung and colon cancers, medical issues related to the reproductive systems and organs, sexuality and/or gender, hyperhidrosis or excessive sweating, psoriasis, leprosy, irritable bowel problems, obesity, depression, anxiety, schizophrenia, borderline personality disorder, men seeking therapy, people who serve in the US Military requesting support and assistance for PTSD and other mental health challenges, medications, poverty, being incarcerated, having a legal record or history, substance use/abuse, and suicide. We will discuss several of these topics at length throughout this course. There will be practical approaches to suicide prevention discussed in appropriate sections of this curriculum.

In our role as Peer Support Specialists, we need to work to educate ourselves and others about the negative impacts that stigma has on individuals, communities, and our world as a whole. We also need to be positive role models of personal recovery for others and be living, breathing examples of what it means to be accepting of others, nonjudgmental, and holding people in unconditional positive regard at all times. We can do this by using promoting recovery values and a recovery environment, by using recovery language, being willing to talk openly about topics that are frequently stigmatized, encouraging equality between physical health and mental health, meeting people where they are on their recovery journey, showing compassion for all people – no matter what they are experiencing, showing unconditional positive regard for people, promoting community wide regard for all people, empowering people instead of shaming them, not stigmatizing ourselves by being honest about ourselves and sharing our stories in a hopeful and helpful manner, and letting other people (including the media) know that they are being stigmatizing.

By doing these things, we will be empowering our peers, colleagues, and others in the community to see people from the perspective of a wellness identity, as opposed to assigning them an illness identity, which will help them to continue to be held in community wide regard. Through our examples, this will help other people in our communities and in the world learn how to hold all people in unconditional positive regard, regardless of whatever challenges they might be experiencing. We will also be developing and building professional peer relationships.

Think about and answer these questions:

- Do you consider yourself to use stigmatizing language or recovery language more often? Why do you think you use this type of language?
- How can recovery language be empowering to someone in their personal recovery?
- What can you do to create and maintain a recovery environment?

- What can you do to reduce stigma in your community, online, and throughout the world?
- What would be an appropriate approach for a Peer Support Specialist to take with a person served who talks about suicide?

"We have to get the word out that mental illnesses can be diagnosed and treated, and almost everyone suffering from mental illness can live more normal lives."

– Rosalynn Carter

11. p. 23-27: Positive Role Model – Read introduction of Recovery Values and answer in writing the eleven (11) questions on these pages.
12. p. 24-25: Recovery Environment – How can you develop this with the person served?
13. p. 25-27: Define stigma and write two (2) ways you, as a PSS, can reduce stigma in your community.

Section I, Part Seven: Qualities of an Effective PSS

To be effective Peer Support Specialists, we need to possess and exhibit certain qualities, as we reach out to, engage with, empower, and support others. These qualities help us to develop and build professional peer relationships.

They:

- Emphasize ability versus disability
- Are aware that diagnoses may be changed, may be similar, and may even be missed by professionals
- Are willing to want to share one's own Recovery story (self-disclosure) in an effort to bring Recovery to another individual
- Model Recovery in every facet of community life (lead by example)
- Have the ability to listen, communicate, and connect; to disconnect and reconnect when necessary
- Have the ability to ask for support when there seems to be a disconnect and to reconnect
- Are aware of maintaining personal boundaries

- Have compassion
- Are trustworthy
- Have the ability to be intentional in thought, word and deed
- Are present in the moment (mindful) and relinquish the need to control
- Maintain confidentiality
- Work at being non-judgmental
- Have the knowledge and ability to respond rather than react
- Practice proactive thinking that results in behavior that reduces impulsivity and habitual negative reactions
- Have insight to inner strengths and weaknesses
- Be mutually honest and communicate effectively
- Seek to gain new knowledge and information through trainings and experience
- Are able to complete required forms and other documents
- Are able to connect people with the resources they need
- Are able to negotiate and renegotiate safety, support, and help
- Empower people to focus on personal recovery and wellness identity
- Use Recovery Language whenever possible
- Share messages of hope and acceptance
- Work to create and maintain a recovery environment
- Empower and support peers to educate themselves and make their own informed choices and decisions
- Other qualities from class…

14. p. 27-28: Qualities of an Effective PSS – Be familiar with the qualities and identify those that will be difficult for you to embrace. Put your thoughts in writing.

Section II, Part Twelve: History of Mental Health and Recovery

The world will little note nor long remember what we say here, but it can never forget what they did here. … It is rather for us to be here dedicated to the great task remaining before us – that from these honored dead we take increased devotion to that cause for which they gave the last full measure of devotion – …

—President Abraham Lincoln

The Gettysburg Address

It is with much reverence that we begin this section. Many have gone before who left us abruptly, never to be seen or heard from again. Others of us do not know the torture and feeling of imprisonment which were part of the American 18th, 19th, and 20th centuries. The landscape is changing.

Some smuggled letters are just recently being found, held and embraced by loved ones from past generations. These are the whispered family stories of Uncle Jack and Granny Bessie that are coming to us decades, perhaps, centuries later. This history has been hidden because the stories were either not spoken about at all or told in half-truths. It became, therefore, a family history of secrets buried with the person about whom we knew nothing or little. Since we lived primarily in agrarian societies and large urban areas there was little chance that necessary social structures would be in place in order for the truth to be told, recorded, and preserved.

We dedicate this section to all who came before who had lost HOPE before the world recognized their unique differences. We applaud their pure strength, determination, and faith to endure and persevere! We are beginning to learn a lot from many and that information will become helpful to future generations so the suffering which was tolerated will never be repeated.

We usually talk about stigma being the single most important barrier as identified in our WRAP classes for “Things That Held us Back.” So, if it is an identifiable barrier, we wish to do something to reduce/remove stigma as a priority. What better way than to investigate the history of Mental Health which we have come to understand is very well buried under many layers of social, medical, legal and bureaucratic strata.

Come join us on this early expedition as we dig through those layers of fears, tears, and heartache. Come prepared with an open and inquiring mind, a shovel, and a box of tissues!

Consider these Questions:

- Why is Mental Health History Important?
- Why do YOU think it has been a “hidden” history?
- Why is it important to unearth the history?
- What is the connection between this archeological dig and “stigma”?

EARLY HISTORY OF MENTAL HEALTH

Note: None of the ancient languages developed a word for "history"... because "history" as we understand it today was known as "memory." Now, that is something worth thinking about for the particular history about which we are reading!

From the beginning, HOPE (WRAP Key Concept 1) and SUPPORT (WRAP Key Concept 5) were recognized as being essential for survival. That's why our ancestors lived in villages where tribal customs included offering up hope in the face of loss and danger. (Some people today still do). People in our villages were culturally similar. Individuals were not nearly as judgmental as individuals in our society today because we were all "peer." We had not yet found the necessity of excluding others and labeling them as "different" because our cultures were "flat." Who did not have a challenge? It rarely occurred to us to set somebody apart because they had different ways of approaching life. If they were excluded for any reason, the community welcomed the individual into the circle of trust which existed for survival. Universal good was the goal.

Enter commerce, travel, dispersion, power struggles, and greed and we may go somewhere with the early villagers looking something like those having to prove their goodness by being the same… same appearance, same mannerisms, same styles of communication, even same dreams and aspirations. Even Job, after his many traumatic experiences, was affected and his faith tested, but he was given continuous support by family and community.

In promising to describe the history, we were implicitly promising to demonstrate the need for change… for measuring how far we have come and how far we have to go. Part of the research involved in preparing this segment was difficult to uncover. This is a hidden history in many aspects because the topic has been somewhat hidden since the inception of intentionally applied stigma. When and why did we find it necessary as a society to exclude, rather than to include, based on the premise of a perceived "invisible" difference?

THE LIVES THEY LEFT BEHIND: SUITCASES FROM A STATE HOSPITAL ATTIC

Project Willard, New York: A beautiful scenic summer destination point for well-heeled Northeasterners for over a century, situated on one of the historic "Finger Lakes" in Upstate New York. Hidden in the obscurity of the town's history was the greatest local revenue producer and employer, Willard Insane Asylum. An architecturally significant and prominently situated local landmark, the actual internal mechanism was a secret, hidden or not discussed… until recently.

This exhibit has "come out of the attic" for one and all to view and attempt to make sense of the findings. The patients were generally referred to by their assigned numbers only so their numbers became their identities. In our exercise, we have included the numbers as well to make that obvious, albeit painful point, although the names (at least first or last) have now been learned by the archivists.

Who?

#22040 - Mademoiselle Madeline

She was from a very well-to-do French family and loved to travel. She was intellectual and well educated and even graduated from The Sorbonne, in Paris. After World War I, she traveled to, and eventually settled in New York City. She got a very good job and then taught French literature at private girls' schools in Boston, Dallas, New Hampshire, and New York. She enjoyed learning and reading and even took several advanced classes at Columbia University and Hunters College.

She became more and more interested in the world of the occult (which was gaining in popularity with the middle and upper classes at that time). This seemed to alienate friends, coworkers, and employers. Many of them thought she was "odd, tactless, and domineering." During the Great Depression, she was unable to find steady work, and was referred to the Emergency Work Bureau, where they found her "unemployable" and referred her for outpatient mental health treatment. This led to her being admitted to the psychiatric unit at the famous/ infamous Bellevue Hospital in 1931, by her friends and family because they did not like her behavior and beliefs.

Mademoiselle Madeline resisted being hospitalized and constantly refused to submit. She assumed that her voluntary admission to Bellevue Hospital would be temporary, and never expected to be transferred to Willard State Hospital in 1939, after spending time at a few other institutions (Central Islip and Kings Park State Hospitals) on Long Island, New York. During her time at Central Islip, Madeline forcefully and passionately demanded, "I want out of here immediately. I think it is an outrage to be brought here." In 1965, she was still insistent upon her release, her records show she told a hospital worker, "I don't like this hospital. I resent being detained and wasting my time."

In the 1950s, she was given antipsychotic drugs and from those medications, developed extremely debilitating side effects that severely impacted her movements that later came to be recognized as Tardive Dyskinesia (or TD). In 1970, her medical record stated that she had "fidgety movements rigid stances, and facial grimaces" that were not attributed to the drugs. Instead, they prescribed "attitude therapy" to get her to stop making facial grimaces. When she was 79 years old, she was sent to live at a private board and care facility close to the hospital. She died at the age of 90 in that nearby facility after spending most of her life at Willard and advocating for her discharge – sometimes "we know too much and speak too well."

#27967 - Mr. Frank

Was born in 1909 in Columbus, Ohio. He came to New York City, when he was 20, and found work as a chauffeur. He was also an amateur boxer. He enlisted in the United States Army in 1941, and went overseas to serve his country in World War II. He received a medical discharge from the Army in 1944, and returned to New York City.

In June of 1945, shortly after returning from the war, was eating lunch at the Virginia Restaurant in Brooklyn, New York. He was served a meal on a cracked plate. He became upset and caused a disruption outside the restaurant, where he was seen yelling and kicking garbage cans. The police were called, and instead of arresting him, they brought him to the psychiatric ward at Kings County Hospital. From there, he was transferred to Brooklyn State Hospital, and in April of 1946, he was transferred to Willard State Hospital. He was just one of a growing number of African American patients that had been transferred there, from New York City, in the 1940s, due to overcrowding. In 1949, Mr. Frank was transferred from Willard State Hospital to the Veterans Administration (VA) hospital in Canandaigua, New York. Then in 1954, he was again transferred to the VA hospital in Pittsburgh, Pennsylvania. In 1984, 30 years later, he died there, after having spent more than half of his life in an institution.

Mr. Frank was probably experiencing was being triggered due to his service in the war. This was more than likely a symptom of what we now know as Post Traumatic Stress Disorder, which was not understood at that time. This was long before we knew the struggles which many returning veterans experience.

#14956 - Mr. Lawrence

Mr. Lawrence served in the Royal Austrian Army when he was a young man. After he was discharged from the Army, he became a licensed tinker – someone who collected scrap metal and repaired metal objects. Around 1900, was a challenging time for him. He experienced a head injury from a stone throw, he struggled with binges of heavy drinking, and he was admitted to a mental hospital in Dusseldorf, Germany for the first time, where he was noted to be "singing, whistling, and generally noisy." He stayed there for less than one year.

In 1907, Mr. Lawrence immigrated to America from Galicia – what is now known as Austria – and became a cleaner and window washer at the Bellevue Hospital. He lived onsite, in a workers' dormitory. One day in 1916, he was rather boisterous while doing his work: his records indicated he was "loud, boisterous, singing, shouting, praying, and claiming to hear the voice of God." *(USA TODAY 12/5/07, Craig Wilson, reporter)* "and seeing the angels, then again accusing himself of having sinned too much. Alcohol was also involved in this incident. (http://www.suitcaseexhibit.org/index.php?section=thesuitcases&subsection=lawrence) He was taken across the street to the hospital and was committed, and later that year, he was transferred to Central Islip State Hospital, where he was reported to be "extremely restless and noisy, singing, and shouting, and whistling in a boisterous manner." In 1918, he was transferred to Willard State Hospital. He was diagnosed with Dementia Praecox, what we know today as Schizophrenia, and inebriate, or a drunkard.

For many years, he was reported to be volatile and difficult, and sometimes reclusive. In the 1930s, it was discovered that he worked well alone, if he was left to himself. He worked as a cleaner in the hospital superintendent's house, and in 1937, he became the official (unpaid) grave digger for the institution. He experienced some relief from the daily routine on the wards. During the warm weather, he was permitted to live in a small shack on the grounds of the hospital's cemetery, and only coming back to the hospital to eat. In 1945, he wrote a letter to the superintendent of the hospital, requesting his release, stating that he had dug more than 600 graces by hand in eight years. Mr. Lawrence continued to work, digging more than 1,500 graves, until a few days before his death, at age 90, in 1968. He was laid in an anonymous grave in the very same cemetery that he took care of.

Yes, he was buried at the Willard Cemetery, in an anonymous grave, in the ground he once nurtured and sowed. His grave was marked only by his number, as was the case with all 5,776 of those who died and were buried there. In May of 2005, some of Mr. Lawrence's extended family members placed a memorial plaque in the cemetery to remember him.

#32643 - Mr. Dmytro

Mr. Dmytro had experienced a great deal in his life, even before he made it to America. He was born into a poor Ukrainian farm family in 1916, his father died two years later. He was forced into slave labor by the Nazis in World War II. At the end of the war, he tried to make his way back home, and he was captured by the Soviets and sent to an internment camp in Hungary. Later, he was able to escape, and made his way to Vienna, Austria, where he was able to take refuge in an American displaced persons' camp. While he was at the camp, he met and married a Polish woman named Sophia, and they emigrated to American in 1949. They settled in Syracuse, (upstate) New York, and there were able to find good jobs and were welcomed by the Ukrainian immigrant community. Sophia became pregnant, and Mr. Dmytro began building a house for their growing family.

Mr. Dmytro was so thankful for everything that they had, as well as being welcomed and accepted by his new country, so he built a model of the Ukrainian church in his home village and delivered it to President Truman. The church model was displayed in a government office in Washington, D.C., for several years, and everything seemed to be going well for them. Soon after that, Sophia died during a miscarriage, and Mr. Dmytro's life began to fall apart.

In the process of grieving over his wife's death, Mr. Dmytro came to believe that he was supposed to marry Margaret Truman, President Truman's daughter. He visited Washington, D.C., in 1952, and attempted to visit her at the White House. The United States Secret Service detained him and sent him to St. Elizabeth's Hospital in Washington D.C. He was returned to Syracuse, New York, and committed to the Syracuse Psychopathic Hospital before being sent to Willard State Hospital in 1953.

For many years, Mr. Dmytro had difficulty at Willard State Hospital. The staff couldn't understand his extremely thick Ukrainian accent, and he was even given 20 electric shock treatments, which, as you may imagine, did nothing to improve his condition. In the early 1960s, Mr. Dmytro began attending Occupational Therapy sessions and it became apparent that he had a passion and talent for expressing himself creatively through painting. According to hospital staff, Mr. Dmytro painted a painting a day, visually telling the story of his life. His artwork was displayed locally and in Washington D.C., at an exhibit of art done by patients. A few of his paintings have been found, because he generously gave them away to staff who admired his work. Mr. Dmytro stayed at Willard State Hospital until 1977, when he was discharged and sent to a county home. While he was there, and afterward, when he was transferred to a nursing home, Mr. Dmytro continued to paint, and even decorated the walls with murals. He died in 2000, at 84 years old.

The record for someone being housed at Willard the longest is help by a woman named Josephine. We don't know much about her, except that she was first admitted to the Long Island Hospital & Home in 1894, when she was 20 years old, with a diagnosis of Melancholia, which we now know as depression. She was admitted to Willard State Hospital in 1899, at 25 years old, with a diagnosis of Dementia Praecox, which we now know as Schizophrenia. We do not know if she was discharged from the previous hospital and was able to return to her home, or, it is much more likely that she was directly admitted to Willard State Hospital, straight from the previous hospital. She remained at Willard until her death in 1975. She was 101 years old.

Numerous patients at Willard State Hospital had immigrated alone to this country, many from around the turn of the last century, and mostly from Europe. They wished to escape cruelties and atrocities there with the full intention of sending for their family members back in the "old country," once they became settled and economically able to do so. Sometimes, this never happened for reasons we have alluded to earlier. In several recently documented cases, there were concentration camp survivors committed to Willard. Can you imagine having survived that horror only to find forced and free labor here in the land of the free?

We are learning more fully on a daily basis the need for being **Trauma-Informed!** In fact, the state of New York has created a special unit within the Department of Health to screen at every opportunity for the possibility of trauma, particularly from within psychiatric, both inpatient and community based, settings. It recognizes that many people may be experiencing a natural human response to a catastrophic life event which would require a unique approach of support. These iatrogenic responses may sometimes become more difficult to move away from than the original/presenting issue. Frequently, the consequences are longer lasting because people may become stuck, both literally and figuratively.

Many reasons for commitment to Willard and languishing there were simply natural human responses to life's adversities… such as the young husband who "inappropriately" grieved his young wife's death during childbirth, or like the woman who dared to have the courage to leave her philandering and abusive husband. Many others were unemployed and lived in poverty from which they could not escape. Others were lonely and isolated. Their lives were coming apart and no amount of advocacy, good behavior, good works, or faith – one woman was a Dominican nun – seemed to matter.

What? Almost total annihilations, professional atrocities, invisible scars, visible scars from lobotomies, friends dying in their arms, freedom and trust violated, stigma expanded, little information about patients, including next of kin contact information, if families were known; families were not always not notified of significant events, including death.

When? Opened as Willard Asylum in 1869 and became Willard State Hospital in 1890. Willard closed in 1995 with 4,000 patients in residence and after some 50,000 people passed through its halls during a 126 year history. According to Dr. Peter Stastny, one of the authors of the book profiling the finding in the attic, "People did not leave there unless it was in a box." In other facilities spanning the 18th, 19th, and 20th centuries, we found similar, but well concealed, potential situations during our research.

Where? Willard, New York, as well as institutions across this nation, including Dorothea Dix in North Carolina.

Why? In a civilized society, is there an explanation? A discussion of Social Justice does little to explain the attitude associated with the atrocities. At the time, the rationalization may have been: "These patients were deemed incurable, locked in and locked up forever." This reflects the universal thought of the day as related in the book, "The Lives They Left Behind: Suitcases from a State Hospital" by the author, Dr. Peter Stastny.

This incredible body of work, both visual and verbal, is visionary. The burden which was so great has become a gift from those at the helm: Peter Stastny was a psychiatrist with the New York Department of Health when he was called in 1995 by the curator of the New York State Museum, Craig Williams, to assist him with the project of documenting the 427 found suitcases in the attic as Willard was closing.

Dr. Stastny consulted with cinema photographer Lisa Rinzler for her expertise of visual archiving. Additionally, Darby Penney became involved in this 10 year project of documenting contents of the suitcases and attempting to put the pieces of the lives in the puzzle together, giving meaning finally to those who had existed there.

It is interesting to note that more was known about the building itself than was known about the occupants. The Second Empire designed building was proudly registered on The National Register of Historic Places in 1975. It currently houses a prison for drug-abusing parolees. Dr. Peter Stastny is currently Associate Professor at Albert Einstein College of Medicine. As of this research and writing, no family member has retrieved their loved one's possessions.

The people mentioned above deserve a round of thanks for bringing this story from the shadows. It is currently a traveling exhibit. For its debut in Albany, New York, over 60,000 people attended.

The time is here and now for those of us interested in Real Reform and Real Recovery to carry the banner of possibility. This is one time which we hope will be a harbinger of the future that, "When people have problems, their biographies usually disappear." As those noted above said about Willard, "They have managed to move from being hidden in the crevices of an institution to being in a room of their own. Now they can talk to us and share who they are."

Unfortunately, there have been many institutions through the years that have treated people with disabilities, whether they are physical or mental, so badly, that we don't even want to read or hear about it. But, we need to know what has happened, so that we do not let this heinous behavior go on. And it was not just "way back when," at places like Willard State Hospital, but in much more recent times, like in the 1930s, and even up into 2020 – even right here in North Carolina.

DOROTHEA DIX

Dorothea Dix (1802-1887) was a distinguished social reformer. She was a pioneer in mental health and prison reform, as well as taking the lead for women during the Civil War as the Union Army's Superintendent of Female Nurses. She recognized early on that many individuals were being held in prison instead of being treated for emotional and medical conditions in a hospice-type arrangement with an attendant wellness atmosphere. She campaigned, lobbied, and advocated for the right of this service to exist for over twenty years. Dorothea Dix was instrumental in the founding or expansion of more than 30 hospitals for the treatment of people who had mental illness. She was lovingly, and sometimes apprehensively, known as "Dragon Dix." She may have created one of the early cracks in the proverbial glass ceiling.

By the year 1848, North Carolina and Delaware were the only two of the original Thirteen Colonies without "Asylums for the Mentally _______." (Fill in the blank with any one of many disturbing and archaic terms.) Off Dix went to many different locations in North Carolina to explore the possibilities for such a place of retreat and refinement for those who most needed a healing place.

Dix completed an exhaustive study, presented her findings and choice of location to the North Carolina Legislature. After failure, negotiation, re-negotiation, (and while nursing a prominent Senator's wife), the bill passed the North Carolina House and Senate on December 30, 1848. The fiscal appropriation was for only $ 7000. Citizens of means who were able to donate land, food, equipment, and additional dollars did just that after yielding to her convincing and selfless arguments. Many people were convinced that her good works were a genuine effort to actually serve those among us in a humane manner without regard to a bottom line, as we would say today. "Dragon Dix" boasted that donating to her cause really was donating to *her* cause… and with her, "what you saw and what you heard was what you got!"

She insisted that the organization NOT be named for her as was the desire of most of those in support of her efforts. She relented to allowing the area to be named "Dix Hill" but not "Dorothea Dix" anything! Dix Hill admitted the first person on February 22, 1856.

DEINSTITUTIONALIZATION

Another factor to consider in our mental health history timeline is **deinstitutionalization**, which began in the US in 1955 and catalyzed by **The Community Mental Health Bill of 1963**. This is the concept of replacing long-term psychiatric hospital stays with less isolated community-based alternatives, such as supported housing, assertive community treatment teams (ACTT) and other local, state and federal initiatives.

Some say this was a means of reducing costs; however; according to people and organizations on the other side of the issue, there seems to be to **The Olmstead Decision,** issued in **1999**, reinforced the right of individuals to live in the least restrictive environment in their own communities rather than in institutional placements.

Deinstitutionalization had sound concepts at its heart. However, population growth has far outpaced the availability of adequate beds in psychiatric hospitals over decades.

In 1970, there were 413,066 mental health beds in the US; by 1998, there were only 63,526. *(Source: Wikipedia).* According to data cited in *The Shortage of Hospital Beds for Mentally Ill Persons* (March 2008), there were 340 public psychiatric beds available per 100,000 U.S. citizens in 1955. By 2005, the number plummeted to a staggering 17 beds per 100,000 persons.

While hospitals have been emptying – even closing – most communities still lack comprehensive and appropriately coordinated discharge planning services, as well as limited community alternative options. Many people have nowhere to go but the streets, homeless shelters, and often to jails or prisons. As unacceptable as long term hospitalization may be, these outcomes are even less so. Today in North Carolina, about one third of all people who are homeless, and up to one fifth of those incarcerated, have mental health struggles. *(Our Journey Home: 10-Year Plan to End Chronic Homelessness in Pitt County.)*

As reported in The *Olympian* (Washington) on October 9, 2003, “40 mental health hospitals have closed in the last decade, according to US Justice Department and, during the same period of time, 400 new prisons have opened.” Rykers Island Prison in New York, Cook County Jail in Chicago, and the Los Angeles County Jail are currently the three largest *de facto* psychiatric facilities in the US.

COMMUNITY–BASED CRISIS INTERVENTION

Human voice, human touch, and having a heart – being human – is especially important when supporting someone in crisis. In this electronic-driven world, we sometimes need to hear a real voice connected to a real person. For that very reason, many communities have implemented hotlines for emergency or crisis situations, and warm-lines for making that connection and keeping a person safe. These resources usually have a toll-free number to streamline access from any location. In talking with the caller, a hotline operator may activate a mobile crisis team to wherever the person is located.

The purpose of mobile crisis is to intervene in situations where an individual's mental or emotional condition may result in behavior that poses an imminent danger to self or others. Mobile crisis teams (MCT) visit people in their homes or community sites, and others meet individuals in clinics or hospital emergency rooms. The team often includes a number of different types of mental health workers, including a psychiatrist, Registered Nurse (RN), Licensed Clinical Social Worker (LCSW), psychologist, and Peer Support Specialist (PSS). In North Carolina, MCT was one of the first paid positions that called for a Peer Support Specialist. Please refer to your notes at the end of this manual for resources and services available in your area.

PARADIGM CHANGE: HISTORY OF THE PEER MOVEMENT AND RECOVERY WITH REFLECTIONS ON SOCIAL JUSTICE

We envision a future when everyone with a mental illness will recover.

— New Freedom Commission on Mental Health, 2003

So how did we come to “know what we know?” How did we learn that there might be a better way to become inclusive and embracing? When did we realize that we could benefit from discovering the beauty and newness of another’s story? Did others endure the same pain, struggles, and invisibility, but ultimately make meaning of it?

The historical answers are plentiful and may surprise you. The origins of the “Peer Principle” are found in the early Native American community as “Peer Guides.” As early as 1750, Native American recovery or sobriety “circles,” which, under the tradition of “wounded healers,” – the belief that recovery from a devastating illness is a sign of a healer. These sobriety circles were led by tribe members who members who had survived their own battles with alcohol. The leaders of these groups used their own recoveries from alcohol use to establish abstinence-based healing and religious and cultural revitalization movements that called for the complete rejection of alcohol and a return to ancestral traditions.

Sobriety circles focused on a reconnection to community, recovering people supported by an even larger cultural community. This also led to the formation of new abstinence-based Native religions which include some of the longest lasting frameworks for recovery from alcohol use within Native communities. These movements led to the “Indianization of Alcoholics Anonymous” movement beginning in the in the 1960s, and, most recently to the Wellbriety movement, which is a blend of all of the movements that preceded it, and focuses on physical, psychological, relational, and spiritual health – an affirmation of the interconnectedness of all aspects of one’s life.

In France, in the late 1700s, Jean Baptiste Pussin, the governor of Bicêtre Hospital in Paris, France, recognized the value of hiring recovered patients to work as hospital staff. Philippe Pinel, who was the chief physician at the hospital, recognized these peer staff as being “gentle, honest, and humane,” “averse from active cruelty,” and “disposed to kindness.” Hiring former patients marked a shift in the philosophy of mental health care that ushered in the “moral treatment” era. This wasn’t just an isolated case – peer staff were hired in several other inpatient settings, as well.

From the 1840s to 1900s in this country, temperance missionaries appeared after self-disclosure. Many of these missionaries formed addiction recovery mutual aid groups including the Washingtonians in the 1840s, fraternal temperance societies from the 1840s to the 1870s, ribbon reform clubs from the 1870s to the 1890s, Drunkard’s Club in the 1870s, and the United Order of Ex-Boozers in 1914. Groups of physicians came together for addiction removal and “healing of the head” from 1850 to 1920.

At about the same time there was thought, not necessarily movement, in the US on all fronts in terms of pairing up “peers,” there were other smaller and equally effective movements designed to bring attention to and reform the idea of somebody being different and being held without promise of appeal, against his will, forever.

In 1908, there was a resulting outcry to the autobiography published by Clifford Beers, “A Mind that Found Itself,” describing his experiences in mental “asylums.”

This provided the impetus needed for those who were outraged to think this sort of thing would/could happen in America… better yet, in Connecticut! The Connecticut Mental Hygiene League was soon formed, and it is the first of the support groups as we know support groups today.

Surprisingly, European countries like Switzerland started the peer/mentoring/ sponsor process consistently on a maintenance basis by 1877. Everybody seemed to understand Reisman’s Recovery slogan from 1965, “To get it, you have to give it away.”

Alcoholics Anonymous (AA) which began in 1935, as well as and other 12-step groups from the 1930s had active networks in place. Additional recovery support groups that formed included Alcoholics Victorious in 1948, Narcotics Anonymous in 1953, and after that came many other 12-Step adaptations, adjuncts to AA including the Calix Society and Jewish Alcoholics Chemically Dependent Persons and Significant Others (JACS), Celebrate Recovery, and alternatives to AA such as Women for Sobriety, Secular Organization for Sobriety (SOS), and LifeRing Secular Recovery, SMART Recovery, as well as many faith based recovery ministries.

The “modern” concept of Peer Support reemerged again in 1965, when Robert Carkhoff and Charles Truax, who were lay counselors that had been trained with specific skills, were successfully helping patients hospitalized for mental health reasons. Professionals in community mental health settings were some of the first people to begin to advocate for the integration of peers into primary care settings. In 1967, Emory Cowen suggested a community health care model that required nonprofessional peers to be hired and specifically involved in the development, implementation, and evaluation of community interventions. Community mental health care focused on primary care, matching the needs of the people, and employing “indigenous nonprofessionals” (or peers), in the development, implementation, and evaluation of intervention programs. This was in stark contrast to the system of care that was provided by large state hospitals at the time.

In the 1970s, many of the large state hospitals across the country were being closed down and discharging patients with severe mental illnesses into the community, where there was very little to no transitional support. At the same time, patients began to speak out against systematic abuse and mistreatment, as well as, denial of their basic human rights while under the care of these big state mental hospitals. After they were released, former patients sought relief through autonomous peer and mutual support groups, which helped to empower individuals, as well as members of the ex-patient community to come together and advocate for themselves.

Survivors of the radical and harmful treatment that they had endured while in the psychiatric hospitals came together to support each other in a way only they could truly understand. These peers understood that there is so much more to recovery than medication and symptom management. This later process of people coming together has gone by several names over the years: The Consumer Movement, The Psychiatric Survivors’ Movement, The Survivors’ Movement, and the Ex-Patient Movement. Through the years, ex-patients and their allies have focused on human and civil rights, reducing and, hopefully, eliminating prejudice and discrimination through social, political, and legal equality, for the right to self-definition and self-determination, and for alternatives to the medical model. Their ultimate goal is to and work toward a brighter future where the general public will recognize the full humanity of people with psychiatric disabilities. Through coming together and sharing their stories, they helped each other to heal. This was the beginning of peer support as we know it today.

The philosophy of peer support was quickly and widely embraced by people who utilized mental health services, however, the mental health profession, as a whole, was slow to adopt peer support. This became known as the mental health consumer movement. Within this self-help movement, there are many great examples of peer supporters who began advocating during that time who were a strong force of change behind the dissemination, adoption, popularization, and growth of peer support, both within and outside of the mental health system.

Peer support is an evidence-based practice that is considered to be extremely beneficial in many regards. So much so, that it has also been applied to the fields of chronic disease management (including diabetes, mental health, heart disease, cancer, asthma, HIV/AIDS, and substance use/abuse), screening and prevention (cancer, HIV/AIDS, and infectious diseases), and maternal and child health (breastfeeding, nutrition, and post-partum depression).

In the 1980s, the mental health consumer movement reached out to governmental and professional organizations. This led to improved mental health care practices, increased funding for technical assistance and training programs, and a significant increase in peer support services. Peer Support Specialists in the field of mental health were among the first to become certified, and to qualify for Medicaid and state reimbursement.

Nothing About Us Without Us

"Nothing About Us Without Us" is a phrase that was, and still is, used by disability advocates in their quest for justice, equal opportunities, and reasonable accommodations. There was a growing spirit of independence for people who have disabilities and their supporters. In the early 1940s, rubella and polio were on the rise, and becoming more noticed. As the diseases affected more people, awareness was being raised. Summer camps and rehabilitation centers were being established.

The 1960s and 1970s was really the time where a whole generation of people were meeting each other, living their lives, and preparing themselves to be some of the leading activists in the modern civil rights movement. Ed Roberts was one of these activists. He was the first student who uses a wheelchair to attend the University of California in Berkley. There were no accessible dormitories (because that legislation had not yet been developed, passed, and enforced), he lived in the campus hospital. He was the inspiration for the development of the first Center for Independent Living. There are now more than 400 Centers for Independent Living that are run by and for people who have disabilities who do not live in nursing homes or other institutions.

In the 1980s, more and more public figures with disabilities were coming into the limelight and providing representation for people who have disabilities. People like Ray Charles, Stevie Wonder, B.B. King, and Robert Winters, just to name a few, were more in the forefront than ever before. Television shows like "Sesame Street" was highlighting actors and guests who have disabilities, as well as topics related to disabilities.

For a long time, and sometimes, even to this day, the portrayal of people who have disabilities in the media is inaccurate and flawed. Many characters, including villains, in movies, on television, or in books are shown to have a certain disability or challenge, whether it be an amputated limb (Captain Hook), or "mental problems" as many others like the Joker in the Batman movies or Randle McMurphy in the book and movie "One Flew Over the Cuckoo's Nest."

This was a time when lawmakers were finally jumping on the bandwagon and making the effort to create and enact meaningful legislation that will support people who have disabilities by providing them with opportunities, and prohibiting discrimination. They needed significant encouragement to do so.

On April 5, 1977, demonstrators marched outside of government buildings in many cities across the United States, including San Francisco, California. They were protesting to have the regulations enforcing Section 504 of the Rehabilitation Act of 1973 signed. The actions taken by these courageous protestors are now referred to as the 504 Sit-Ins.

A you will learn later in Section II: Part Twelve, this prohibited agencies who received financial aid from the United States federal government from discriminating against anyone who has a disability. More than 100 people entered the offices of the federal Department of Health, Education, and Welfare, and stayed for several weeks. They were successful, and the regulations were signed on April 28, 1977.

In July of the next year, a group of 19 people gathered at one of the busiest intersections in Denver, Colorado, and got out of their wheelchairs and proceeded to lay down, which stopped traffic. They were demonstrating for the accessibility of Denver's public transportation system. They had been pushing the city to install wheelchair lifts, and became angry when a new fleet of buses was released without them. Their brave actions led to the creation of the Americans Disabled for Accessible Public Transit (now the American Disabled for Attendant Programs Today or ADAPT) in 1983. The group quickly expanded to have many chapters throughout America. This group also pushed for transportation provisions to be included in the Americans with Disabilities Act.

In 1982, a little boy who had Down Syndrome, as well as some other physical issues related to having a blocked esophagus, was born into a family in Bloomington, Indiana. Doctors told the little boy's parents that they should not have a surgery to help the little boy and un-block his esophagus. Disability rights activists tried to intervene, but Baby Doe (as he later came to be known) starved to death before legal action could be taken. The Surgeon General of the United States at that time, Dr. C. Everett Coop, said that the boy was denied food and water not because the treatment was unnecessarily risky, but because the baby was intellectually disabled, which was a decision he did not agree with.

Later the next year, a little girl was born on Long Island, New York, with an open spinal column. Her parents decided to not have her undergo surgery, even though it would have helped her to live longer. This little girl later came to be known as Baby Jane Doe. President Ronald Reagan's administration called for "Baby Doe squads" to be established. Baby Doe squads were government officials, including child protective services workers, went to hospitals to inspect reports of discrimination against newborn babies with illnesses. The situations of those two families led to the Baby Doe Amendment to the Child Abuse Law in 1984, where guidelines were created for the treatment of newborn babies who have illnesses.

In 1856, in Washington D.C., a school, that included housing, was established for 12 deaf students and 6 blind students. The mission was to create educational opportunities for deaf students. In 1864, President Abraham Lincoln signed a bill into law that allowed that institution to be able to confer college degrees. In 1894, part of this school's name was officially changed to Gallaudet College.

Through an act of Congress in 1954, the whole school's name was changed to Gallaudet College, in honor of the man who started that first school, so long ago. Gallaudet College became a University in October 1986 (by another act of Congress) and continues to be a leading center of learning providing students the opportunity to complete an undergraduate or graduate education in liberal arts.

In March of 1988, the university appointed a president who was not deaf. From its inception 132 years before, the university had never had a deaf president. Many students came together to protest and started a movement that became known as Deaf President Now (DPN). The university hired their first deaf president, I. King Jordan, and their first deaf chair for their Board of Trustees, Philip Bravin, both of whom had previously graduated from the educational institution. DPN was a very important moment in deaf civil rights history, because it paved the way for people who are deaf and hard of hearing to show their determination and be self-empowered. The university does admit a small percentage (up to 5%) of hearing students each year.

In the spring of 1990, the Americans with Disabilities Act (ADA) legislation stalled in Congress. On March 12 of that year, hundreds of undaunted demonstrators left their wheelchairs and crutches, and began to crawl up the steps of the Capitol building. Their purpose was to bring awareness to the injustices of inaccessibility that the "reasonable accommodations" clause in the ADA was supposed to remedy. This event became known as the Capitol Crawl. Many of the protestors were arrested. One protestor, Anita Cameron, stated that she had been arrested 139 times in her fight for disability rights. Lex Frieden, an expert on disability policy who helped to create the ADA, stated, "I think on that day and at that time, more people learned about disability discrimination and equal opportunity than we can imagine."

Barriers to accessibility are not just physical, like curbs, crosswalks, and steps. Accessibility includes technology, as well. In 2006, the National Federation of the Blind filed a class-action lawsuit against the Target Corporation, stating that the Target company's website was not accessible. The court made the decision that the Americans with Disabilities Act (ADA) applies to websites that have a connection to a psychical place of public accommodation (like a brick and mortar store), and that Target must modify the website to make it accessible. Accessibility in this fashion includes captions and descriptions for all pictures, videos, images, charts, etc., as well as other modifications.

We would be remiss if we did not discuss the topics of disability and how race and police brutality are related. About 30% – 50% of all people killed by law enforcement officers are disabled, according to a study by the Ruderman Family Foundation. Disability was not included in the media and news reports when they provided information about the deaths of Sandra Bland, Eric Garner, Freddie Gray, and many others. Instead, they used the term "underlying conditions" to refer to depression, asthma, and high blood pressure – "a euphemism that is bent to make people feel like they're not murdering people," said Cyrée Jarelle Johnson, a Black disabled poet and librarian. Other statistics to take into consideration include that, according to the Centers for Disease Control (CDC), Native people have the highest rates per capita of police brutality. Mx. Deerinwater, who is with the organization Crushing Colonialism, said "that 'per capita' piece is always critical when we talk about any issue related to Natives because we're a little less than 2% of the United States population."

Another extremely significant and valid concern of Vilissa Thompson, a social worker and the founder of the blog 'Ramp Your Voice!' and other people like her is this: confrontations with the police. She shared, "I'm someone who's hard of hearing and if I cannot hear a command that's given to me by law enforcement, that can make me appear to be noncompliant." This also is true for people who have Autism and other disabilities where communication is a significant challenge. Unlike Thompson, they may hear the command given, but they may not be able to respond in a "socially acceptable manner" or maybe not at all. This should be a serious cause for concern. In Section IV, Part Two, where Navigating the Legal System is discussed, Crisis Intervention Teams are mentioned. More education and training for law enforcement officers, and really for everyone, about how to assist people who have disabilities, before, during, and after a crisis, as well as at other times, is absolutely necessary to ensure the safety, security, and welfare for all people, whether they have disabilities or not.

Support, Recognition, and Disability Pride

At the 1993, International Conference on Autism, in Toronto, Canada, Jim Sinclair (one of the founders of Autism Network International), gave a speech that became know as part of the foundation for what has become known as the Neurodiversity Movement, which holds the belief that cognitive differences are part of normal variations of human behavior. In this speech, he said, "You didn't lose a child to autism, you lost a child because the child you waited for never came into existence. That isn't the fault of the autistic child who does exist, and it shouldn't be our burden. Grieve if you must, for your own lost dreams, but don't mourn for *us*. We are alive. We are real. And we're here waiting for you." Sharon daVanport, who was the founding Executive Director of the Autistic Women & Nonbinary Network, wrote, "Neurodiversity affirms that everyone deserves to be accepted and included for who they are." As Peer Support Specialists, we should also be practicing acceptance and inclusion of everyone.

In 1990, the first Disability Pride parade was held in Massachusetts. At first, this seemed a bit unusual, but after the city of Chicago, Illinois, held it's first Disability Pride parade in 2004, these events became much more commonplace across the country. Disability pride can be a complicated topic that many people are in favor of, but they also believe that there is still a great deal of work to be done in the area. Eli Claire, a writer and activist who was the Grand Marshall of Chicago's Disability Pride parade in 2010 said, "Pride is tricky. Pride often only comes to us after we have some community and after we have some politicized framework around who we are."

How Do We Know Recovery Works?

As early as 1939, researchers were beginning to follow patients to see how well they "Recovered." Almost 50 years ago, in several different parts of the world, some of the first long term studies about recovery were being published. These studies followed people for many years and held them to extremely strict standards for recovery.

The numbers in the outcomes section of the chart on the next page may seem a bit low overall, but when we look at the extremely high standards that these studies used to determine "Recovery" and is a person was "Recovered," the low numbers seem higher related to the very high standards of recovery. The standards that these studies used to determine is a person had "recovered" or not include:

> *"The universal criteria for recovery has been defined as no current signs and symptoms of any mental illness; no current medications; working; relating well to family and friends; integrated into the community; and behaving in such a way as not to being able to detect having ever been hospitalized."* (Harding)

I know people who have never been hospitalized for mental health challenges who are not even up to these standards of recovery. This just goes to show how high these standards of recovery really are. Basically, this shows us that recovery is possible! And that it is possible for everyone!

Name of Person who Completed Study, Date, & Location	**Size** **(How Many People were in the Study?)**	**Number of Years** **(How Long was the Study?)**	**Outcomes** **(How Many People Recovered?)**
Bleuer (1972) Zurich, Switzerland	208	23	53 – 68 %
Huber (1975) Bonn, Germany	502	22	57 %
Ciompi & Muller (1976) Berlin, Germany	289	37	53 %
Tsuang (1979) Iowa City, Iowa, USA	186	35	62 – 68 %
Harding (1987) Waterbury, Vermont, USA	269	32	62 – 68 %
Ogawa (1987) Gunma, Japan	140	22.5	57 %
Desisto (1995) Maine, USA	269	36	49 %

People who experience mental illness or other mental health challenges, and/or struggles with addiction, like people who have diabetes, heart disease, or many other conditions, can learn how to manage their symptoms and challenges effectively, maximize their wellness, realize their true potential, and go on to attain lives rich in meaning, productivity, and genuine satisfaction. Once we see recovery in these terms, we can embrace meaningful recovery possibilities for everyone, regardless of symptoms, diagnoses, and/or disability levels.

No history of mental health and recovery would be complete without discussing stigma and its effects. Even throughout the growth of the Recovery and Peer Support movements, stigma still reared its ugly head. The advocacy of everyone working together to promote recovery and positive change was able to reduce stigma (at times). But we need to continue to do all we can to break down the divisive barriers that stigma builds up.

Mental Health and Recovery Reform in the United States and in North Carolina

The road to acceptance and inclusion of all people and recovery reform in the United States, and in North Carolina, has been quite extensive, with twists and turns and ups and downs over the last couple of decades. We would like to start this section with some brief explanations before summarizing some of the legislation that regulates mental health care services throughout the country and in our state.

Unfortunately, the people of this country (and others), were not always as accepting, nonjudgmental, and welcoming as we are today. Some of this came as a result of people's beliefs, culture, and/or what was going on in the world at that time. As we mentioned in Section II, Part Nine, when we learned about beliefs, perspectives, and how and why we know what we know, and in Section II, Part Eight, when we read about and discussed the things that influence how we see the world, we remember that many different things shape our worldview.

We know that it is necessary to question "how we know what we know" as well as asking, "Do we know as much as possible?" "Is something possibly hidden here?" If so, "What and why?"

HISTORY

We have to learn a little bit about history and what has happened in the past, so that we can be more aware of things, notice any red flags if/when they arise, and take appropriate action to have a more open, understanding, and inclusive future for everyone.

We read earlier about the terrible treatment of people who were institutionalized, as well as the brave, outspoken individuals who dared to speak up and advocate for others to create necessary positive changes. Regrettably, there have been more violations of personal freedoms and rights that have been done to people in history – not just people who have disabilities, but people who have been marginalized for reasons related to race, identity, beliefs, behaviors, and many others; and/or people who can be found on the fringes of society. It is our duty to inform ourselves to prevent future injustices from happening.

Most North Carolinians believe the Civil Rights Movement occurred strictly in the 1960s with the start of the Sit-ins at the lunch counter of the Woolworth's store in Greensboro, North Carolina. The movement, however, began much earlier and one can argue that its roots lay in the Civil War period. The Civil Rights Movement was an effort, among many things, to overturn segregation, commonly known as Jim Crow, legislation.

The Civil Rights Movement, as it commonly known, began in the 1950s. In 1954, the U.S. Supreme Court issued its Brown decision, and schools were ordered to desegregate. Meanwhile in the 1950s, North Carolina blacks started what would become known as sit-ins.

There were many bold individuals who rose to the occasion to share their beliefs that they should be treated equally. Kelly Alexander reorganized the chapter of the National Association for the Advancement of Colored People (NAACP), based in Charlotte North Carolina, and emerged as one of the Tar Heel State's principal civil rights leaders during the 1950s and 1960s.

On February 1, 1960, four students from North Carolina Agricultural & Technical College, sat down at the lunch counter in the Woolworth's store in Greensboro, where the official policy was refuse service to anyone who wasn't white. Even though they were denied service, the four young men refused to leave. Police arrived, but were unable to take action, because the demonstration was peaceful. They stayed until the store closed, and then came back the next day. Because of coverage in local media and on television, in less than a week, there were more than 300 other students that had joined their protest at Woolworth's and other local businesses. This demonstration gained national attention and set an example for many others to follow throughout the segregated south.

Soon after, in April of 1960, the Student Nonviolent Coordinating Committee (SNCC) was formed in Raleigh, North Carolina. The Congress of Racial Equality (CORE), along with the SNCC, sponsored the Freedom Rides in 1961, where black and white bus riders boarded Greyhounds and Trailways buses and challenged segregation on the buses and in bus stations all over the southern United States. This historic March on Washington, in 1963, where Dr. Martin Luther King, Jr. so passionately shared his famous "I Have a Dream" speech with more than 250,000 people.

In 1965, as a result of more demonstrations, some peaceful, but many were violent, even deadly, the **Voting Rights Act of 1965** was signed into law by President Lyndon B. Johnson. This legislation prevented racial discrimination in voting. It was designed to enforce the voting rights established in the 14th and 15th amendments of the United States constitution. This act was amended 5 times over the years to expand its coverage.

In 1900, the eugenics movement began to take hold in the United States. Eugenics is the study of how to arrange the reproduction of species to include traits that are desirable to be passed down to future generations. Instead of focusing on selective breeding to pass on positive traits, the movement focused on preventing people from having the ability to reproduce, in order to eliminate negative or undesirable traits. In 1907, Indiana became the first state to pass a "compulsory sterilization law for criminals, idiots, imbeciles, and rapists." It did not take long for more than one third of states to created laws that allowed for the involuntary sterilization of people who were "deemed undesirable for procreation." In 1927, the United States Supreme Court agreed with state compulsory sterilization laws – a ruling that has yet to be overturned. As a result, between 1907 and 1963, more than 64,000 people had been involuntarily sterilized.

During this time, information about eugenics had reached across the world, and specifically to Germany. When Adolf Hitler rose to power in the 1930s, he did so with knowledge of eugenics, who helped form his incorrect beliefs that German people had become weak as a result of defective genes that had been passed down through the population. The Nazi regime used eugenic propaganda to promote the Aryan race as the most superior race above all others. This is what gave them the foundation to create and enforce those policies, starting in 1935, when the Nuremburg Laws were created. These laws prohibited marriages and sexual relations between Germans and people who had Jewish ancestry. Other policies included German married couples to undergo genetic testing to determine if there were any hereditary diseases, as well as the restriction of contraception and abortions for German couples.

Many Germans did not want to be reminded of people who they felt like "did not measure up" to their concept of a superior race. Many of these people they considered to be "unfit" or handicapped." Within their viewpoint, people who had physical and mental disabilities were deemed as "useless" to society, and "unworthy of life" as they were believed to be a threat to the pure genetic lines of the Aryan race. At the beginning of World War II, in 1939, Adolf Hitler authorized these killings under the T-4 or euthanasia program, which required the cooperation of many German doctors who reviewed the files of people housed in institutions in order to determine who should be killed. The doctors also supervised the actual killings, which were done by specially built gas chambers at six institutions throughout Germany and Austria, by lethal injection or starvation.

In his quest for the most superior race, Hitler did unspeakable, atrocious things and had more than 6 million Jewish people, and more than 5 million people who were not of Jewish decent killed. Many of the 5 million others were people who were Romani (or Gypsies), people who had physical and/or mental disabilities, priests, communists, resistance fighters, trade unionists, people of Polish decent, other people of Slavic decent, Jehovah's Witnesses, anarchists, and people who identified as homosexual. All of these people whose lives were cut brutally short were valuable human beings with strengths, knowledge, abilities, positive qualities, and gifts to share with the world – even if Hitler and the Nazis didn't see it that way.

The forced involuntary sterilization did not just apply to people in other parts of the United States, but hit closer to home. In North Carolina, sterilization laws were passed in 1919 and 1929, and the Eugenics Board was formed in 1933.

Initially, some sterilization laws were deemed unconstitutional in court, and the purpose of the Eugenics Board was to ensure the constitutionality of those laws. They created an appeal process, which from then on, made the process constitutional. Soon after the board was created, they began receiving petitions from specifically designated institutional or county officers requesting sterilization of certain people. The Eugenics Board practiced negative eugenics (discouraging reproduction by people having genetic or defects or presumed to have inheritable and undesirable traits).

After the Eugenics Board received the petition for sterilization, they attempted to gain consent, although the process seemed to be more of an obstacle, rather than to allow the person to completely understand what was about to happen to them and provide them the choice to make fully informed decision. If consent was not given, then the Eugenics Board went to the person's next of kin, spouse, or legal guardian (depending upon the case). People who did not personally give consent had the right to submit an appeal. For 10 to 15 minutes, the Eugenics Board heard the person's case and then decided whether to order a forced sterilization.

The North Carolina eugenics program has been criticized as being inherently racist and sexist. Until the 1960s, more white people were sterilized than African Americans. During the 1960s, when social workers had the authority to recommend sterilizations, the number of African Americans skyrocketed (approximately 99%). Throughout the Eugenics program in North Carolina, 6 out of 7 sterilizations were performed on women. North Carolina Closed down the Eugenics Board in 1977.

Sterilizations were performed, according to the reports from the Eugenics Board, for the public good. The Eugenics Board stressed the positive aspects and avoided calling people who had been sterilized criminals or delinquents, and made an effort to remove any stigma from people who were sterilized. The members of the board truly believed that sterilization improved the lives of those who underwent the procedure.

SOCIAL JUSTICE AND LEGAL CHANGES

In July of 1946, the **National Mental Health Act** (NMHA) became law. This legislation created the National Institute of Mental Health (NIMH) and also provided grants and fellowships for training mental health professionals and "research related to the cause diagnosis, and treatment of neuropsychiatric disorders." One key provision that was left out of this law was the financial support for institutional care and treatment of people who have mental illness.

The **Mental Health Study Act of 1955** was passed and called for "an objective, thorough, nationwide analysis and reevaluation of the human and economic problems of mental health" and authorized the Public Health Service to provide grants for the study. A direct result of this act was the report from the Joint Commission on Mental Illness and Health, entitled Action for Mental Health, which was published in March of 1961. This report called for and laid the groundwork for "wholesale system reform, including a redefined role for state mental hospitals as smaller, more intensive treatment sites." This also leaned more toward community-based treatment and deinstitutionalization.

In 1956, the **Social Security Act** (originally passed in 1935) was amended to include the provision of monthly benefits to permanently and totally disabled workers from ages 50-64, benefits for children with disabilities (over 18 years old) of retired or deceased workers, if their disability began before age 18. Many other amendments were made to this legislation throughout the 1950s. The Social Security Disability Insurance (SSDI) program was later amended to include benefits for people with mental disabilities. In 1972, Congress also amended this act to provide income support for people whose age or disability made them incapable of holding a job. This became known as Supplemental Security Income, or SSI.

In 1964, the **Civil Rights Act** was signed into law. This prevented people from being discriminated against because of their race, color, religion, sex, or national origin. This was just the beginning, and certainly a step in the right direction, but there was still a long way to go.

The **Amendments to the Social Security Act of 1965** was the legislative action that created Medicare and Medicaid. These entitlements were enacted in 1965 and offered health insurance for older Americans (age 65 and older), people living in poverty, and Americans who have disabilities. Medicare and Medicaid are not without their limitations, though. Medicare limits coverage for care in public and private psychiatric hospitals to a lifetime 190 days (a little over 6 months total).

Medicaid, which is the joint federal and state program that provides funding for acute (short term) care and long term care in nursing homes and other settings, specifically does not cover funding for care of non-elderly adults in state psychiatric hospitals and other "institutions for mental disease." Institutions for mental disease, or IMDs, are defined as a hospital, nursing facility, or other institution of more than 16 beds, that is primarily engaged in providing diagnosis, treatment, or care of persons with mental diseases, including medical attention, nursing care, and related services.

Unfortunately, in order to get the much desired funding, states began moving tens of thousands of their elderly patients with mental disorders from state mental hospitals to nursing homes. This was not beneficial to those older people who were being moved, because many of the nursing homes that they were moved to provided no psychiatric care and the overall quality of care varied widely. The death rate for the people who had been moved, increased dramatically as a result of the poo quality or complete lack of appropriate care.

In 1968, and again in 1975, Congress passed laws that expanded the role of Community Mental Health Centers (CMHCs) to include services for people who abuse substances, children, and the elderly. Regrettably, the fundamental issue of providing for the basic human and medical needs of people with severe mental illnesses was never addressed in that legislation.

In 1970, North Carolina began the North Carolina Medicaid Program, which was then under the jurisdiction of the NC Department of Social Services, and is now under the direction of the NC Department of Health and Human Services (DHHS), which was previously the Department of Human Resources. In 1972, Medicaid services were expanded to include inpatient mental health services for people over 65 years old, and to also include mental health centers.

In 1970 and 1972, respectively, Congress created the National Institute of Alcohol Abuse and Alcoholism, and the National Institute on Drug Abuse. They are both part of the National Institute of Mental Health. In 1974, all three institutes became part of the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA), under the United States Department of Health, Education, and Welfare.

As a response to the national legislation related to community mental health centers, in the early 1970s, North Carolina clustered the 100 counties into area 501(c)3/nonprofit organizations called Mental Health/Developmental Disabilities/ Substance Abuse Services (MH/DD/SAS) Authorities. While some counties with larger populations became their own, stand-alone authorities, most of the counties were grouped together to meet federal catchment are population requirements, and to ensure that resources were available to many of the less populated, more rural areas. In accordance with the community based philosophy, all accountability in the area authority model was placed with local citizen advisory/area governing boards.

In 1973, President Richard Nixon signed The Rehabilitation Act into law. This was one of the first federal civil rights laws that protected people who have disabilities from discrimination. The Rehab Act, as it is commonly referred to, applies to all the organizations and employers that are part of (or funded by) the federal government.

This includes federal contractors and subcontractors.

The Rehabilitation Act of 1973 has several sections that mandate civil rights for people who have disabilities. Some of those key sections are:

Section 501: This section requires federal agencies to establish and maintain affirmative action plans for recruiting, hiring, placing, and advancing people who have disabilities in federal employment. It also prohibits federal agencies from discriminating based on disability, and it requires that agencies make reasonable accommodations for qualified applicants and for employees with disabilities.

Section 502: This section created the United States Access Board, whose motto is "Advancing full access and Inclusion for All." The US Access Board is tasked with ensuring compliance with the Architectural Barriers Act of 1968 (ABA), and to provide technical assistance relating to Title II and Title III of the Americans with Disabilities Act (ADA), with regard to architectural, transportation, communication, housing, and attitudinal barriers. Additional duties of the Access Board include creating standards for accessible telecommunicaitons equipment and customer premises equipment and electronic and information technology, as well as promoting accessibility throughout all segments of society.

Section 503: This section creates a benchmark for a desired percentage of people who have disabilities in the workforce of covered employers. The goal is for these federal employers to have (or show progress toward having) a workforce that consists of at least 7% of people who have disabilities. Section 503 is enforced by the United States Office of Federal Contract Compliance Programs (OFCCP).

Section 504: This section was designed to protect people who have disabilities from discrimination lased solely on their disability in services and programs that receive federal funds. These services and programs include government agencies, and projects receiving federal financial assistance, such as Section 8 public housing, K-12 schools, almost all colleges and universities, and vocational training schools. There were several lawsuits that arose related to Section 504 and key disability rights concepts. The concepts included in this litigation are reasonable modification, reasonable accommodation, and undue burden.

Section 505: This section includes information regarding any actions taken to enforce or charge a violation of the Rehabilitation Act, courts may award a reasonable attorney's fee as part of the costs.

Section 508: In the 1998 amendment to the Rehabilitation Act, Section 508 was created and it prohibits the federal government from procuring electronic and information technology goods and services, including websites, that are not fully accessible to those with disabilities.

The Rehabilitation Act was amended in 1974 and defines what a disability is. According to this definition, a person with a disability is someone 1) with a physical or mental impairment that substantially limits one or more major life activities; 2) who is regarded as having such an impairment; and 3) with a record of such impairment.

The Education for All Handicapped Children Act (now the Individuals with Disabilities Education Act or **IDEA)** was enacted in 1975, and it required all federally funded public schools to provide equal access to education, as well as one free meal a day to children who have disabilities. This legislation was passed after a number of lawsuits were filed by parents. This education law has become a model for other disability laws.

In 1977, President Jimmy Carter formed the **President's Commission on Mental Health**, which focused on people who had long term mental illnesses and other people who were underserved (like children, the elderly, and people who have long term illnesses). The final report from this organization advocated for the creation of a national health insurance program that would cover mental health care as the best means of assuring the people with mental illnesses would have access to necessary services.

Just before the presidential election of 1980, Congress passed the **Mental Health Systems Act**, which established a federal and state system that ensured care and treatment in community settings for people who have mental illness, and also included people in those previously mentioned underserved groups.

President Ronald Reagan was elected and reversed many of the policies that President Jimmy Carter had put into place. With a new president, comes a new administration, and more often than not, there are serious changes are made. One of these changes was that the nationwide system that was envisioned by the Mental Health Systems Act was never put into place. However, in 1981, at the urging of President Reagan, Congress passed the **Omnibus Budget Reconciliation Act** (OBRA). The OBRA provided a block grant to states for mental health and substance abuse services. The OBRA did significantly reduce federal funding for mental health, and completely reversed nearly 30 years of leadership and participation in mental health policy. This shifted the focus back to the states, and also increased the financial burden for the states and local communities. In response to the passage of this legislation, the North Carolina General Assembly met for a special session in October of 1981, and passed laws restricting visits to mental health centers to only 18 per year, along with other restrictions.

The North Carolina Persons with Disabilities Act preceded the Americans with Disabilities Act (ADA) and became law in 1985, and "ensures the equality of opportunity, promotes independent living, self-determination and economic selfsufficiency, and encourages and enables all persons with disabilities to participate fully to the maximum extent of their abilities in the social and economic life" of North Carolina, and allows for them to "engage in remunerative employment, to use available public accommodations and public services, and to otherwise pursue their rights and privileges as inhabitants" of North Carolina, and prevents discrimination of people who have disabilities in North Carolina, because it "results in a failure to realize the productive capacity of individuals to their fullest extent."

The North Carolina Persons with Disabilities Act defines the term "disability" a bit differently. Related to that legislation, disability means "a physical or mental impairment that substantially limits one or more major life activities, having a record of such an impairment, and being regarded as having such an impairment.

Being 'regarded as' having such an impairment means an individual has a physical or mental impairment that does not substantially limit major life activities but that is treated as constituting such a limitation; has a physical or mental impairment that substantially limits major life activities because of the attitudes of others; or has no physical or mental impairment but is treated as having such an impairment." This law also defines a physical or mental impairment as any physiological disorder or abnormal condition, cosmetic disfigurement, or anatomical loss.

The North Carolina Persons with Disabilities Act applies to employers who have 15 or more employees. It does not apply to employers whose only employees are domestic or agricultural workers who work at the employer's home or residence.

In 1986, the United States Congress enacted the **State Comprehensive Mental Health Services Plan Act**. This requires states to "develop and implement plans for community-based services for people with severe mental illness." In 1988, Medicaid was expanded to include case management services for "chronically mentally ill individuals."

The Americans with Disabilities Act of 1990 (ADA), is also a civil rights law that prohibits discrimination against people who have disabilities in all areas of public life, especially jobs, schools, transportation, state and local governments, businesses and nonprofit service providers, accessibility through communication and telecommunication, and all public and private places that are open to the general public. The ADA also includes more specific information about inclusion and accessibility. Titles II and III of the ADA set enforceable standards related to accessible design for new construction, alterations, program accessibility, and the removal of barriers. The purpose of the ADA is to ensure that people with disabilities have the same rights and opportunities as everyone else does.

The ADA uses the same definition of someone who has a disability that the Rehabilitation Act does.

In 1996, Congress passed the **Mental Health Parity Act (MHPA)**. This legislation applied to large employer-sponsored group health insurance plans and prohibited them from imposing higher annual or lifetime dollar amount limits on mental health benefits than those that were applicable to medical and/or surgical benefits. The MHPA did not mandate coverage for mental health treatment, but it only applied to group health insurance plans that offered mental health benefits. This law was a step in the right direction, but there was a great deal missing from this legislation. As a result, many states, including North Carolina, began passing their own laws related to mental health parity. In 1999, President Bill Clinton directed the Office of Personnel Management to begin mental health parity in the Federal Employees Health Benefits plan coverage.

In July of 2000, the North Carolina General Assembly took legislative action and created the **Legislative Oversight Committee for Mental Health, Developmental Disabilities, and Substance Abuse Services.** The purpose of this legislation was to develop a plan to implement the recommendations of the State Auditor. This also let to new guidelines for the new mental health care system for a 5 year period from 2001 until 2006. This changed the “Area Agency” model to a similar “Local Management Entity” (LME) model that gave counties greater governmental involvement over personnel and financial decisions. The LME model went into effect in January of 2007. Under this LME model, the previous Area Authorities, who had been receiving the federal money, as well as providing people services to meet their needs related to mental health, developmental disabilities, and substance abuse services, were required to divest the provision of their MH/DD/SAS services to community-based agencies, while they changed to LMEs and continued to manage the federal and state funding for these programs.

The legislation also created the **Trust Fund for Mental Health, Developmental Disabilities, and Substance Abuse Services and Bridge Funding Needs**. The use of the fund was limited to providing start up funds and operating support for community based alternatives for people currently residing in state institutions; facilitating compliance with the Olmstead decision; expanding and enhancing treatment and prevention programs in order to eliminate waiting lists; providing bridge funding during transitional periods resulting from the closure of state institutions and departmental restructuring; and constructing, repairing, and renovating state MH/DD/SAS facilities.

In 2007, the Centers for Medicare and Medicaid Services (CMS) awarded significant grants to 30 states and Washington DC. This was called the Money Follows the Person Rebalancing Demonstration, or Money Follows the Person for short.

The purpose of Money Follows the Person was to assist stated in their efforts to move toward the community based model for long term care for the elderly and people who have disabilities (people who are eligible for Medicaid), and reduce their dependence on institutional care. This money was to help transition people out of institutional settings and into more appropriate placements within their communities. The more appropriate placements may be inpatient facilities, people's own homes, or another less restrictive setting than an institution.

The ADA was amended in 2008 and this is called the **Americans with Disabilities Amendments Act of 2008**. These amendments expand the definition of "disability" and describes "major life activities" more in depth. The ADA Amendments Act of 2008 describes major life activities to "include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working." It also describes major life activities to include "the operation of a major bodily function, including but not limited to, functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions." The ADA Amendments Act goes on to explain more specifically what does and does not qualify as a disability that substantially limits a major life activity, and how to determine that. It also includes language that reads "physical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society, yet many people with physical and mental disabilities have been precluded from doing so because of discrimination; others who have a record of a disability or are regarded as having a disability have also been subjected to discrimination."

There are several agencies that assist people in accessing the resources they need when it comes to disabilities. The Equal Employment Opportunity Center (EEOC) has developed fact sheets, a Small Business Center, as well as additional resources for employers of all sizes, veterans, and youth.

Also in 2008, the **Mental Health Parity and Addiction Equity Act** (MHPAEA) was passed. This legislation created guidelines for group health insurance providers that provided coverage for mental health and/or substance use disorders to maintain parity, or equality, between those benefits and the benefits that they provide related to medical and/or surgical benefits. This lifted many of the previously enforced restrictions and allowed for there to be more access to, and coverage for, necessary services for mental health and/or substance use disorders – similar access to, and coverage for mental health and/or surgical services. This also included similar costs for copayments and deductibles.

This also expanded the parity requirements of the Mental Health parity Act of 1996, where there were no longer lifetime annual dollar limits on mental health or substance use disorder benefits that is lower than the lifetime annual dollar limits imposed on medical or surgical benefits.

A key part of this legislation was that, for the first time, substance use disorders were addressed and included in parity law. There are still limitations within this legislation, because, unfortunately, not everyone is subject to parity – some plans and benefits like some Medicaid fee-for-service options, employers with fewer than 50 employees who self-insure, and self-funded non-federal governmental health insurance plans that opt out. These plans are not required to provide equitable coverage. Even with the parity laws, Medicare still has the 190 day lifetime limit on inpatient psychiatric care, that does not apply to inpatient medical or surgical care.

In 2010, the **Affordable Care Act (ACA)** was signed into law by President Barack Obama. This legislation, along with the Health Care and Education Reconciliation Act of 2010, encompasses the most comprehensive overhaul of the healthcare system in the United States. This also included significant expansion of the Medicaid program and the expansion of mental health parity, specifically expansion of mental health and substance use disorder benefits and federal parity protections in the following ways: including mental health and substance use disorder benefits in the Essential Health Benefits; applying federal parity protections to mental health and substance use disorder benefits in the individual and small group markets; and by providing more Americans with access to quality health care that includes coverage for mental health and substance use disorder services.

MENTAL HEALTH REFORM IN NORTH CAROLINA

In North Carolina, mental health, substance use disorders, and people with intellectual disabilities (distinctions) are managed under the same agency. The Department of Medical Assistance (DMA), a division of NC Department of Health and Human Services (DHHS), serves as the State Medicaid Agency. DMA provides oversight of Medicaid and waiver issues.

The term, 1915(b)/(c) Medicaid Waiver, refers to two sections of the Social Security Act that allow states to apply for waivers from federal Medicaid policy. These waivers that are in effect in North Carolina are lengthy, but we will attempt to highlight what we feel are the portions that are likely to affect those working as peer support specialists.

It may be important to note here two portions of the waiver that deal with "statewideness" and "freedom of choice." Chapter 122C (Mental Health, Developmental Disabilities, and Substance Abuse Act of 1985) is the North Carolina statute that "regulated" mental health care services in this State. This law outlines the management, funding and governing aspects of those services.

As mentioned earlier in this text, **The Olmstead Decision** passed in **1999** required states to place people with mental health disabilities in to more community based programs and fewer institutions. This case was a ruling that played a major role in how mental illnesses were identified as disabilities under the guidelines of the Americans with Disabilities Act (ADA). The case involved two women, Lois Curtis and Elaine Wilson, who had mental and intellectual disabilities wo were treated in Georgia. The case was brought against Tommy Olmstead, the commissioner of the Georgia Department of Human Resources, and was heard by the United States Supreme Court. In 1999, they ruled that the unjustified segregation of people with disabilities was considered discrimination that violated the ADA.

2001: North Carolina's General Assembly passed the "Mental Health System Reform Act," which required local jurisdictions to separate the management of mental health services from the delivery of those services.

Previously, county programs and area authorities delivered mental health services by directly employing the care providers. This law required the governmental local management entities (LMEs) to contract with private providers for the mental health services needed by residents and to change their focus to system management and oversight.

April 1, 2005: The State of North Carolina, in collaboration with Piedmont Behavioral Healthcare (now Cardinal Innovations Healthcare Solution, created a pilot program using 1915(b)/(c) waiver authorities (see note below). The pilot program allowed the LME to operate as a Prepaid Inpatient Health Plan (**PIHP**) for Medicaid. In essence they were acting in the role of an insurance provider.

Services were provided based on a capitated model, in which a set amount of money each month is paid per person rather than per service. Capitation is used as a means of controlling the growth of health care costs by allowing management providers flexibility to budget money by designating services based on the needs of those served.

According to the State:

“The goals of this capitated health plan initiative are to:

- Better tailor services to the local consumer by adopting a consumer-directed care model and focusing on community-based rather than facility-based care.
- Enhance consumer involvement in planning and providing services through the proliferation of mental health (MH) recovery model concepts.
- Demonstrate that care can be provided more efficiently with increased local control.

December 2006: During its first year of operation, it was determined that the waiver program had generated savings through care and utilization management strategies. The State received approval from the Centers for Medicare and Medicaid Services (CMS) in December of 2006 to invest those savings into additional 1915 (b)(3) services. The purpose of the new services was to provide cost-effective, supplemental services and supports aimed at decreasing hospitalizations and helping individuals remain in or return to their homes and communities when preferred and appropriate.

2010: Due to the success of the capitated service delivery model, the State of NC requested and obtained approval from CMS to expand the model to other LMEs across the State over time. NC General Statute 122C was amended to require the expansion of the waiver program statewide by July 1, 2013.

2011: Legislation was passed requiring the N. C. Department of Health and Human Services (DHHS) to, once again, restructure the management responsibilities for the delivery of services to individuals through the 1915 (b)/(c) Medicaid Waiver.

The Managed Care Organizations (MCOs), formerly called Local Management Entities (LMEs), are the regionally based agencies that receive a set monthly payment from the state to provide both state-funded and Medicaid-funded mental health, intellectual and developmental disability, and substance abuse services around the state. With that money, the MCOs must allot services for everyone under their care. The statute required each MCO, in order to participate in the waivers, to have a catchment area with a population of at least 300,000 by July 1, 2012 and 500,000 by July 1, 2013.

Part of the responsibilities of the MCOs are to ensure that the providers are qualified and certified. They also monitor the services provided by having a coordinator meet with the providers and the people being served to determine if the services are appropriate and beneficial.

A large network of private providers was built up to increase service capacity in local communities across the state. Concerns were raised by advocacy groups about the quality of care because of so many changes so quickly in the system without proper infrastructure to deliver that care.

January of 2012: Western Highlands Network (WHN) was the first of the state's mental health local management entities to convert to the new managed care model, piloted by Piedmont Behavioral Health (Now Cardinal Innovations). By July of the same year WHN board of directors fired the CEO because he had failed to inform them that the agency had fallen $3 million in debt. The agency tried to gain stability, but their contract with the state was terminated in July, 2013.

Efforts were made for a smooth transition of services, as the agency was absorbed into Smoky Mountain Center.

DOJ Settlement - Transition to Community Living Initiative (TCLI)

2012: The State of North Carolina entered into a settlement agreement with the United States Department of Justice. The purpose of this agreement was to make sure that persons with mental illness are able to live in their communities in the least restrictive settings of their choice, in accordance with the requirements of the Americans With Disabilities Act, The Rehab Act, and the Olmstead Decision. The NC Department of Health and Human Services is implementing the agreement through the Transition to Community Living Initiative.

“The Transition to Community Living Initiative (TCLI) has six primary components:

- In-Reach and Transition – Providing or arranging for frequent education efforts and discharge planning targeted to individuals in adult care homes and state psychiatric hospitals. (*This portion is specifically important because MCO’s are required to have an in-reach person who is a peer support specialist*.)
- Diversion – Diverting individuals from being admitted to adult care homes.
- Housing – Providing community-based supportive housing with tenancy supports.
- Supported Employment – An evidence-based service to assist individuals in preparing for, identifying, and maintaining integrated, paid, competitive employment.
- Assertive Community Treatment – An evidence-based treatment and support model of services offering intensive customized, community-based services for people with mental illness.
- Quality Management – using data to evaluate progress and outcomes.

Each component has settlement milestones. Implementation plans are completed during collaborative work group sessions that are open to the public.”

There is still money in this fund that is available through some Local Management Entities/Managed Care Organizations (LME/MCO).

2013: The governing unit of the area authority is the area board. The section of Statue 122C that outlines the makeup of the area boards has been revised several times over the years. However, we just want to note here that the most recent legislation in effect requires no fewer than 11 and no more than 21 voting members. Those members must represent various areas of expertise, including health care management, insurance, finance, etc. and most importantly for our purposes, at least 6 members representing consumers of mental health care services.

Oversight of the waivers is performed by Intra-Departmental Monitoring Teams (IMT) with representation from all divisions within the Department of Health and Human Services (DHHS) involved in the operation of the 1915(b)/(c) waivers. They meet monthly or quarterly with The Division of Medical Assistance (DMA) leading the teams. The Division of Medical Assistance (DMA) retains final decision-making authority on all waiver policies and requirements.

In 2013, the State of North Carolina passed laws to allow the Office of Rural Health to create, implement, oversee, and monitor a statewide telepsychiatry system, to increase access to psychiatric providers. In 2015, specific laws applying to the State of North Carolina went into effect related to increasing parity for people who have mental illness and substance use disorders. These laws increased access to services and health insurance and decreased discrimination based upon diagnosis. Additional laws were passed in 2018 that overhauled the system related to people who are involuntarily committed (IVC) into an inpatient mental health treatment facility.

Some difficult questions to consider and answer related to the history of recovery and mental health:

- Are we ready to embrace the concept of inherent worth which each individual brings to the table?
- Are we applying universal principles and our own and our agencies' values and ethics?
- How would we feel if somebody said, "Who would want to be you?"
- Do we fully grasp the impression of "for the greater good" and how one person's not questioning is able to lead to "group think" or "herd mentality" to expand the concept to include an enormous number of individuals?

We have learned that differences and cultural beliefs can possibly be divisive. As Peer Support Specialists, we should learn about the past, and do our part to be part of the change in order to move forward in a positive manner to help to create a better, open, accepting, nonjudgmental, and inclusive recovery environment for all.

Information in this section was gathered from the following resources:

Willard State Hospital and The Suitcase Exhibit:

http://suitcaseexhibit.org/index.php?section=about&subsection=suitcases

Section 1915(b) Waiver (to the Social Security Act)
STATE OF NORTH CAROLINA NC MH/IDD/SAS Health Plan Renewal; April 1, 2013: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Downloads/NC_Cardinal-Innovations_NC-02.pdf

Demonstrations and waivers… select North Carolina, 1915(b)/(c): http://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/waivers_faceted.html

NC Department of Health and Human Services website (DOJ Settlement): http://www.ncdhhs.gov/mhddsas/providers/dojsettlement/index.htm

Chapter 122C. Mental Health, Developmental Disabilities, and Substance Abuse Act of 1985:
https://www.ncleg.net/EnactedLegislation/Statutes/HTML/ByChapter/Chapter_122C.html

NC Department of Health and Human Services website (Medicaid History): http://www.ncdhhs.gov/dma/pub/historyofmedicaid.pdf

The Affordable Care Act expands affordable Medicaid coverage for millions of low income Americans and makes numerous improvements to Medicaid and the Children's Health Information Insurance Program (CHIP): https://www.medicaid.gov/medicaid-chip-program-information/medicaid-and-chip-program-information.html

http://www.medicaid.gov/affordablecareact/provisions/provisions.html

Rehabilitation Act:
https://northeastada.org/resource/rehabilitation-act

Americans with Disabilities Act:
https://www.eeoc.gov/statutes/ada-amendments-act-2008

https://askjan.org/topics/Americans-with-Disabilities-Act-Amendments-Act.cfm

Native American Recovery:
https://www.thefix.com/content/native-american-sobriety-circles

https://www.narcononarrowhead.org/addiction/alcohol/history-of-alcoholism.html

http://www.williamwhitepapers.com/pr/2002AddictionRecoveryinNativeAmerica.pdf#:~:text=Five%20overlapping%20movements%20have%20provided%20a%20frame work%20for,the%20basic%20text%20of%20Alcoholics%20Anonymous%20%28see%20www.whitebison.org%29.

The Ex-Patient Movement:
https://www.behaviorismandmentalhealth.com/2021/03/03/a-brief-history-of-the-ex-patient-movement/?utm_source=rss&utm_medium=rss&utm_campaign=a-brief-history-of-the-ex-patient-movement
http://suitcaseexhibit.org/index.php?section=questions&subsection=amovementforhumanrights

Mental Health Laws in North Carolina:
https://www.paritytrack.org/reports/north-carolina/statutes/

https://ncleg.net/EnactedLegislation/Statutes/HTML/ByChapter/Chapter_168A.html

https://www.ncha.org/wp-content/uploads/2018/06/One-Page-IVC-Bill-Leave-Behind-June-13.pdf

Mental Health Parity Act:
https://www.healthaffairs.org/do/10.1377/hpb20140403.871424/full/

Mental Health Parity and Addiction Equity Act:
https://www.cms.gov/CCIIO/Programs-and-Initiatives/Other-Insurance-Protections/mhpaea_factsheet

https://www.dol.gov/sites/dolgov/files/EBSA/about-ebsa/our-activities/resource-center/faqs/understanding-implementation-of-mhpaea.pdf

https://echogroupdev.wpengine.com/knowledge-center/understanding-the-mental-health-parity-and-addiction-equity-act/

Money Follows the Person:
https://en.wikipedia.org/wiki/Money_Follows_the_Person

https://medicaid.ncdhhs.gov/providers/programs-and-services/long-term-care/money-follows-person#:~:text=Money%20Follows%20the%20Person%20%28MFP%29%20is%20a%20state,and%20began%20supporting%20individuals%20to%20transition%20in%202009.

Eugenics and Sterilization:
https://home.heinonline.org/blog/2021/06/the-complicated-history-of-eugenics-in-the-united-states/

https://northcarolinahistory.org/encyclopedia/eugenics-board/

https://encyclopedia.ushmm.org/content/en/article/the-murder-of-people-with-disabilities

Nothing About Us Without Us:
https://www.nytimes.com/2020/07/22/us/ada-disabilities-act-history.html

15. p. 28-66: History of Mental Health – Read and focus on the Early History of Mental Health; Dorothea Dix; Deinstitutionalization; Community Based Crisis Intervention; History of the Peer Movement; Historical Events; Nothing About Us Without Us; Support, Recognition and Disability Pride; How Do We Know Recovery Works?; and Mental Health Reform in the United States and in North Carolina, including the legislative actions taken. Put your thoughts in writing and be prepared to actively participate in the group discussion.

16. p. 29 & p. 63: Answer in writing the 4 questions on each of these pages.

17. p. 30-36: Read about the "The Lives They Left Behind." Put your thoughts in writing and be prepared to actively participate in the group discussion.

18. p. 39-66: Create a timeline citing the history of recovery.

Section IV, Part Three: Providing Peer Support When Working with an Agency

Sometimes Peer Support is provided one-on-one by a natural support, but many times, it is provided by someone who is employed by a specific agency as a Certified Peer Support Specialist. This provides a defined and detailed structure for those who are employed in this role.

As mentioned before, first and foremost, we are required to follow the ethical guidelines and values of Peer Support. This means we need to continue to define, and model recovery values, attitudes, and beliefs through our personal actions and in our surroundings. This includes monitoring our own wellness, knowing our strengths and limits, continuously taking care of ourselves (by doing what is in our personal wellness plans, going to support meetings, working a program, whatever we need to do) and keeping ourselves well, and effectively communicating (verbally and/or in writing) to the right people (our supporters, sponsor, supervisor, and/or others) if and when we require additional support and when our personal challenges may interfere with our ability to effectively provide support to other people. We need to continue using person first and recovery language, and share openly, which engenders mutual respect, holds everyone in unconditional positive regard, breaks down barriers, empowers the people we are supporting, and fosters their personal recovery. This creates and helps to maintain a recovery environment that is accepting of everyone, is nonjudgmental, meeting people where they are, is respectful, and negotiates and renegotiates safety and support, which also reduces stigma, as well as develops and improves community wide regard for all people who need support.

If we are employed by an agency, and we are providing Peer Support services, in addition to abiding by the Peer Support ethics, we also need to follow the guidelines set forth by that agency. This includes everything from dress codes, work schedule, confidentiality, codes of conduct, safety procedures (including documentation), job responsibilities of people in specific positions within the agency, professional behaviors, relationships between staff (including which staff members may work together in teams or small groups to provide support to people), supervision, the services that the agency provides (as well as when it may be necessary to refer people who need a different level of support or service that the agency is not able to provide), the usage of offices, equipment, and computers, to time off requests, documentation procedures, emergency procedures, communicating with our supervisor about our wellness including when and how we may require additional support and be realistic about our ability to effectively and appropriately support other people, and our responses to physical, mental, and other crises. Many, if not all, of these things should be covered during the employee’s orientation process, and policies related to these are usually located in the agency’s Standard Operating Procedures (SOP) or Policies and Procedures (P & P) manuals. Depending upon the agency, we may be provided with a hard copy of these manuals (such as in a binder), or they may be stored online on the company’s intranet. Knowing and abiding by these guidelines, as well as our job responsibilities ensures the safety, security, and well being of everyone at the agency – the people who are being supported, as well as the staff.

Sometimes, as part of the orientation process, or prior to hiring someone, agencies require that employees have actively participated in specific trainings covering topics such as CPR, First Aid, Bloodborne Pathogens, HIPAA and confidentiality, workplace environment, how to appropriately respond to and document emergencies or crisis situations, including: nonviolent responses to crisis, what to do when there is a storm, fire, or in the case of there is someone with a gun on the premises, and others. Many agencies will also require that employees actively participate in trainings after they have been hired – usually on an annual basis. Sometimes this is referred to as reorientation. Additionally, agencies may provide trainings or classes provided at different times throughout the year. Some of these trainings may be held on a more frequent basis, (either quarterly or monthly) like fire drills, tornado drills, etc. These trainings help us to grow professionally, to become more knowledgeable, improve our skills and abilities, improve the delivery of services, and to keep everyone safe. Many times, you will receive a certificate after attending and actively participating in those trainings. This is also a form of documentation that you will need to keep up with and most likely submit a copy to you supervisor for documentation. The agency may have employees working in your location facilitating these trainings, or they may be facilitated by someone with an outside agency or organization. Sometimes these are referred to as in-house or in-service trainings. Occasionally, we may be able to use some of these trainings (if they relate to Peer Support or other similar topics) to assist us in the recertification process, that we need to complete every two years if we would like to continue working with people in the role of a Certified Peer Support Specialist in North Carolina.

The agency should also provide us with an accurate job description that lists the job title, purpose, duties and responsibilities, items related to supervision – who will be supervising the person in the position, how often they should meet, etc., the required and preferred qualifications which should consist of education, experience, knowledge, skills, and abilities, and working conditions. The clear expectations set forth in our job description should help us to ensure that we are providing the best peer support possible for the people that we are supporting, as well as holding us to the high standards of being a Certified Peer Support Specialist.

When we work for an agency, as a Certified Peer Support Specialist, or in any capacity, whether we realize it or not, we are a representative of that agency, both when we are working, and when we are "off the clock." We should be aware of how we are perceived (including our actions) when we are out in the community. This includes our personal wellness, as well as times when we may not be well.

If we continue to monitor our wellness and do everything we need to do to stay well, live by recovery and other positive values including honesty, integrity, and authenticity, as well as continue to be competent, respectful, reliable, and professional, we should have nothing to worry about, but sometimes life happens.

This is something we should be aware of, as it does impact us if we are unwell and/or we are possibly exhibiting behaviors or acting in ways that may negatively reflect back on us, the people we are supporting, and on the agency we are working with. Sometimes people we come across in the community may form a negative view or perception of us and also the agency we are working with. Their beliefs may come from their past experiences or as a result of stigma, or from something else altogether. We do need to remember that we cannot control what other people believe, think, or feel, but we do not need the focus of our lives to be on what other people believe, think, or feel, but we do need to be aware of it. This is where empathy comes into play, and why taking care of ourselves and supporting our own wellness is so vitally important. This goes to show the impact of a person's beliefs and stigma and how it can affect they way we are perceived, and how, because we work for a certain agency, that agency is perceived, because we could be considered an extension of that agency.

19. p. 66-69: Providing Peer Support When Working with an Agency – Read and understand. Put your thoughts in writing and be prepared to actively participate in the group discussion.

Videos – Review and Summarize

20. p. 69: Review the videos on the Take Your Heart to Work – Peer Support Playlist (found here – on YouTube: https://bit.ly/TYHW-PeerSupportVideos) *Note: Some of these videos deal with serious and possibly difficult topics. List at least three (3) things from each video that stood out to you.

Articles – Review and Summarize

21. p. 69-81: Review the articles included with this assignment. Read and understand. Put your thoughts in writing and be prepared to actively participate in the group discussion. List at least three (3) things from each article that stood out to you.

Recovery, Rehabilitation and The Conspiracy of Hope

Presented at: "There's a Person In Here": The Sixth Annual Mental Health Services Conference of Australia and New Zealand. Brisbane, Australia

Date: September 16, 1996

Presented by: Patricia E. Deegan, Ph.D.

I would like to thank you for this opportunity to speak with you today. Recently I had the opportunity to go to Australia to deliver a keynote address. The theme of that conference was: "There is a person in here." I really liked that conference theme. There is a person in here: this is such a simple statement yet it is so profound. In many respects coming to know that there is a person in here is the easy part. Remembering to always listen for and to reverence the person over there - that can be the more difficult part. In any case I would like to share that paper with you.

The conference was held in the sub-tropical city of Brisbane where the temperature doesn't get much lower than 80 degrees. That's quite different than where we live. Unlike the tropics, we have four very distinct seasons ranging from the bitter cold of snowy winter, to the muddy season of unfolding colors that we call spring, to the simmering days of summer right through to the spectacular unfolding of autumn when all of the leaves on the trees burst into bright yellows and oranges and reds and then fall to the ground leaving the trees naked and stark and bare. There is always a lesson for me in the cycle of the seasons. I am always reminded that growth happens in a context and that in order for growing things to emerge, environments must change to accommodate that growth.

One spring, after a long and icy winter, I wrote this:

It is springtime and hope is everywhere. It is springtime and it feels like all living things are trembling into being, still wet and new and fragile and determined to put down roots and grow.

I think of a sea rose I watched growing out at a beach near my home this past summer. It is a fragile and tender life, that sea flower. I love to see it. At dawn it moves in a slow upsway as it turns toward the morning star. That sea rose is a light seeker. It bends toward the light. It is a light-seeker whose roots reach way down into the darkness of the earth. In fact, it was in darkness that his new life began.

Way back in January and February, when the icy winds lashed across those dunes and the days were short and the light gave no warmth, even then, way down under the ground, this new life was waiting. Nobody could see it, nobody was there to witness it, and yet this promise of a sea flower waited. It waited in that icy darkness for the sands to begin to thaw. It waited for the rains to come and loosen the earth. And then, ever so slowly, it began to stir. Moving one grain of sand at a time, it began to grow.

It did not grow straight toward the light at first. No. First its growth sought a downward course, reaching, stretching, blindly groping through shifting sands to find a solid place. A place to be rooted. A good soil to cling to and to be nurtured by. A home soil that could sustain it even in driving rains and tormenting winds. And then, having rooted itself in this way, the sea rose began its journey toward the light. Poking through the darkness, that sea flower emerged tiny and lovely and insistent and courageous. On frail and trembling limbs, this small thing rose to a new life…

That sea rose teaches us a lot about hope. It teaches us that hope emerges out of darkness. It teaches us that hope can grow in nurturing environments that allow one to become rooted and secure. And I have come here today to celebrate the hope symbolized by that sea rose.

I believe it is a spirit of hope that gathers us here together today. We are direct service workers and administrators, policy makers and family members, service users and mental health professionals. Fifteen years ago you would never have caught us all in the same room together! Indeed, ten years ago we would hardly even speak to each other! But here we are, gathered together - social workers sitting next to family members who are sitting next to policy makers, who are sitting next to case managers, who are sitting next to academicians who are sitting next to service users... What is going on here? Are the old rules being broken? Is the old order shaking a bit at the foundation? IS THERE A CONSPIRACY GOING ON?

I love the word conspiracy. It comes from the Latin "conspirare" which means to breathe the spirit together. What is the spirit we are breathing together here today?

It is a spirit of hope. Both individually and collectively we have refused to succumb to the images of despair that so often are associated with mental illness. We are a conspiracy of hope and we are pressing back against the strong tide of oppression which for centuries has been the legacy of those of us who are labeled with mental illness. We are refusing to reduce human beings to illnesses. We recognize that within each one of us there is a person and that, as people, we share a common humanity with those who have been diagnosed with mental illness. We are here to witness that people who have been diagnosed with mental illness are not things, are not objects to be acted upon, are not animals or subhuman life forms. We share in the certainty that people labeled with mental illness are first and above all, human beings. Our lives are precious and are of infinite value.

And as we progress through this conference we will be learning that those of us with psychiatric disabilities can become experts in our own self care, can regain control over our lives, and can be responsible for our own individual journey of recovery. And finally, as the sea rose teaches us, we are learning that the environment around people must change if we are to be expected to grow into the fullness of the person who, like a small seed, is waiting to emerge from within each of us.

If we plant a seed in a desert and it fails to grow, do we ask, "What is wrong with the seed?" No. The real conspiracy lays in this: to look at the environment around the seed and to ask, "what must change in this environment such that the seed can grow?" The real conspiracy that we are participating in here today is to stop saying what's wrong with psychiatric survivors and to start asking: "How do we create hope filled, humanized environments and relationships in which people can grow?"

But before speaking further of hope and humanity, I want to share with you what it is like to be diagnosed at a young age with mental illness and to lose all hope. I want to tell you about the dark winter of anguish and apathy when we give up hope and just sit and smoke and drink coffee.

For those of us who have been diagnosed with mental illness and who have lived in the sometimes desolate wastelands of mental health programs and institutions, hope is not just a nice sounding euphemism. It is a matter of life and death. We know this because, like the sea rose, we have known a very cold winter in which all hope seemed to be crushed out of us. It started for most of us in the prime of our youth. At first we could not name it. It came like a thief in the night and robbed us of our youth, our dreams, our aspirations and our futures. It came upon us like a terrifying nightmare that we could not awaken from.

And then, at a time when we most needed to be near the one's we loved, we were taken away to far off places. At the age of 14 or 17 or 22 we were told that we had a disease that had no cure. We were told to take medications that made us slur and shake, that robbed our youthful bodies of energy and made us walk stiff like zombies. We were told that if we stayed on these medications for the rest of our lives we could perhaps maintain some semblance of a life. They kept telling us that these medications were good for us and yet we could feel the high dose neuroleptics transforming us into empty vessels. We felt like will-less souls or the walking dead as the numbing indifference and drug induced apathy took hold. At such high dosages, neuroleptics radically diminished our personhood and sense of self.

As these first winds of winter settled upon us we pulled the blankets up tight around our bodies but we did not sleep. During those first few nights in the hospital we lay awake. You see, at night the lights from the houses in the community shine through the windows of the mental institution. Life still went on out there while ours crumbled all about us. Those lights seemed very, very far away. The Zulu people have a word for our phrase "far away." In Zulu "far away" means, "There where someone cries out: 'Oh mother, I am lost" (Buber 1958, p. 18). And indeed, this is how far away it felt in the mental hospital. The road back home was not clear. And as we lay there in the darkness we were scared and could not even imagine the way out of this awful place. And when no one was looking we wept in all of that loneliness.

But when morning came we raged. We raged against the bleak prophesies that were being made for our lives. They are wrong! They are wrong! We are not crazy. We are not like those other ones over there who have been in this hospital too long. We are different. We will return home and everything will be just the same. It's just a bad dream. A temporary setback.

In time we did leave the hospital. We stood on the steps with our suitcases in hand. We had such courage - our youthful optimism waved like triumphant flags at a homecoming parade. We were going to make it. We were never going to come back to the hospital again.

Some did make it. But most of us returned home and found that nothing was the same anymore. Our friends were frightened of us or were strangely absent. They were overly careful when near us. Our families were distraught and torn by guilt. They had not slept and their eyes were still swollen from the tears they cried. And we, we were exhausted. But we were willing to try. And I swear, with all the courage we could muster we tried to return to work and to school, we tried to pick up the pieces, and we prayed for the strength and perseverance to keep trying. But it seemed that God turned a deaf ear to our prayers. The terrible distress came back and our lives were shattered once again.

And now our winter deepened into a bone chilling cold. Something began to die in us. Something way down deep began to break. Slowly the messages of hopelessness and stigma which so permeated the places we received treatment, began to sink in. We slowly began to believe what was being said about us. It seemed that the system tried to break our spirit and was more intent on gaining, even coercing our compliance, than listening to us and our needs. We found ourselves undergoing that dehumanizing transformation from being a person to being an illness: “a schizophrenic”, “a multiple”, “a bi-polar” (Deegan 1992). Our personhood and sense of self continued to atrophy as we were coached by professionals to learn to say, “I am a schizophrenic;” “I am a bi-polar;” “I am a multiple.” And each time we repeated this dehumanizing litany our sense of being a person was diminished as “the disease” loomed as an all powerful “It,” a wholly Other entity, an “in itself” that we were taught we were powerless over.

Professionals said we were making progress because we learned to equate our very selves with our illness. They said it was progress because we learned to say “I am a schizophrenic.” But we felt no progress in this. We felt time was standing still. The self we had been seemed to fade farther and farther away, like a dream that belonged to somebody else. The future seemed bleak and empty and promised nothing but more suffering. And the present became an endless succession of moments marked by the next cigarette and the next.

So much of what we were suffering from was overlooked. The context of our lives were largely ignored. The professionals who worked with us had studied the science of physical objects, not human science. They did not understand what the neurologist Oliver Sacks (1970) so clearly articulates: “To restore the human subject at the center - the suffering, afflicted, fighting, human subject - we must deepen a case history to a narrative or tale; only then do we have a ‘who’ as well as a ‘what’, a real person, a patient, in relations to disease - in relations to the physical… the study of disease and identity cannot be disjoined… (stories) bring us to the very intersection of mechanism and life, to the relation of physiological processes to biography” (p.viii). But no one asked for our stories. Instead, they thought our biographies as schizophrenics had been already been written nearly a century before by Kraeplin and Blueler.

Yet much of what we were going through were simply human experiences - experiences such as loss and grief and shock and fear and loneliness. One by one our friends, relatives and perhaps even families left us. One by one the professionals in our lives moved on and it became too difficult to trust anyone. One by one our dreams and hopes were crushed. We seemed to lose everything. We felt abandoned in our ever deepening winter.

The weeks, the months or the years began to pass us by. Now our aging was no longer marked by the milestones of a year’s accomplishments but rather by the numbing pain of successive failures. We tried and failed and tried and failed until it hurt too much to try anymore. Now when we left the hospital it was not a question of would we come back, but simply a question of when would we return. In a last, desperate attempt to protect ourselves we gave up. We gave up trying to get well. Giving up was a solution for us. It numbed the pain. We were willing to sacrifice enormous parts of ourselves in order to say “I don’t care.” Our personhood continued to atrophy through this adaptive strategy of not caring anymore. And so we sat in chairs and smoked and drank coffee and smoked some more… It was a high price to pay for survival. We just gave up. And winter settled in upon us like a long cold anguish.

I’m sure that many of us here today know people with psychiatric disabilities who are lost in the winter of anguish and apathy I have just described. It is a time of real darkness and despair. Just like the sea rose in January and February, it is a time when nothing seems to be growing except the darkness itself. It is a time of giving up. Giving up is a solution. Giving up numbs the pain because we stop asking “why and how will I go on?” Even the simplest of tasks is overwhelming at this time. One learns to be helpless because that is safer than being completely hopeless.

The winter of anguish and the atrophy of the sense of self that I am describing is a hell not only for the ones living it, but also for the ones who love and care for us: friends, relatives and even professionals. I have described what it feels like on the inside as it is being lived. But friends, relatives and professionals see the anguish and indifference from the outside.

From the outside it appears that the person just isn’t trying anymore. Very frequently people who show up at clubhouses and other rehabilitation programs are partially or totally immersed in this despair and anguish. On good days we may show up at program sites but that’s about all. We sit on the couch and smoke and drink coffee. A lot of times we don’t bother showing up at programs at all. From the outside we may appear to be among the living dead. We appear to be apathetic, listless, lifeless. As professionals, friends and relatives we may think that these people are "full of excuses," they don't seem to try anymore, they appear to be consistently inconsistent, and it appears that the only thing they are motivated toward is apathy. At times these people seem to fly into wishful fantasies about magically turning their lives around. But these seem to us to be only fantasies, a momentary refuge from chronic boredom. When the fantasy collapses like a worn balloon, nothing has changed because no real action has been taken. Apathy returns and the cycle of anguish continues.

Staff, family and friends have very strong reactions to the person lost in the winter of anguish and apathy. From the outside it can be difficult to truly believe that there really is a person over there. Faced with a person who truly seems not to care we may be prompted to ask the question that Oliver Sacks (1970, p. 113) raises: "Do you think William (he) has a soul? Or has he been pithed, scooped-out, de-souled, by disease?" I put this question to each of us here today. Can the person inside become a disease? Can schizophrenia pith or scoop-out the person so that nothing is left but the disease? Each of us must meet the challenge of answering this question for ourselves. In answering this question, the stakes are very high. Our own personhood, our own humanity is on the line in answering this question. Let me explain:

Sitting in the day room, literally couched in a cigarette smoke screen, the profound apathy and indifference we may encounter in another person will challenge our own humanity and our own capacity to be compassionate. We may question whether there really is a person over there. In such an encounter Martin Buber (1958) would instruct us that the I - Thou relationship is challenged. If we relate to a person as if they were a disease then we enter an I - It relationship. The I-It relationship diminishes our own humanity. Of course, the great work that faces us is to hold the sanctity of the person as Thou, even when the person may be lost to themselves. That is the great act of compassion. To hold the personhood of a person even when they may be lost to themselves. This deepens our humanity or, to paraphrase Martin Buber, I become I by saying Thou (p.11).

However, when faced with a person lost in anguish and apathy, there are a number of more common responses than finding a way to establish an I-Thou relationship. A frequent response is what I call the "frenzied savior response." We have all felt like this at one time or another in our work. The frenzied savior response goes like this: The more listless and apathetic the person gets, the more frenetically active we become. The more they withdraw, the more we intrude. The more will-less they become, the more willful we become. The more they give up, the harder we try. The more despairing they become, the more we indulge in shallow optimism. The more treatment plans they abort, the more plans we make for them. Needless to say, we soon find ourselves burnt out and exhausted. Then our anger sets in.

Our anger sets in when our best and finest expectations have been thoroughly thwarted by the person lost in anguish and apathy. We feel used and thoroughly unhelpful. We are angry. Our identities as helping people are truly put to the test by people lost in the winter of anguish and indifference. At this time, it is not uncommon for most of us to begin to blame the person with the psychiatric disability at this point. We say things like: "They are lazy. They are hopeless. They are not sick, they are just manipulating. They are chronic. They need to suffer the natural consequences of their actions. They like living this way. They are not mad, they are bad. The problem is not with the help we are offering, the problem is that they can't be helped. They don't want help. They should be thrown out of this program so they can 'hit bottom.' Then they will finally wake up and accept the good help we have been offering."

During this period of anger and blaming a most interesting thing happens. We begin to behave just like the person we have been trying so hard to save. Frequently at this point staff simply give up. We enter into our own despair and anguish. Our own personhood begins to atrophy. We too give up. We stop trying. It hurts too much to keep trying to help the person who seems to not want help. It hurts too much to keep trying to help and failing. It hurts too much to keep caring about them when they can't even seem to care about themselves. At this point we collapse into our own winter of anguish and a coldness settles into our hearts.

We are no better at living in despair than are people with psychiatric disabilities. We cannot tolerate it so we give up too. Some of us give up by simply quitting our jobs. We reason that high tech computers do as they are told and, besides, the pay is better. Others of us decide not to quit, but rather we grow callous and hard of heart. We approach our jobs like the man in the Dunkin Donuts commercial: "It's time to make the donuts, it's time to make the donuts." Still others of us become chronically cynical. We float along at work like pieces of dead wood floating on the sea, watching administrators come and go like the weather; taking secret delight in watching one more mental health initiative go down the tubes; and doing nothing to help change the system in a constructive way. These are all ways of giving up. In all these ways we live out our own despair.

Additionally entire programs, service delivery systems and treatment models can get caught up in this despair and anguish as well. These systems begin to behave just like the person with a psychiatric disability who has given up hope. A system that has given up hope spends more time screening out program participants than inviting them in. Entry criteria become rigid and inflexible. If you read between the lines of the entry criteria to such programs, they basically state: If you are having problems, come back when they are fixed and we will be glad to help you. Service systems that have given up hope attempt to cope with despair and hopelessness by distancing and isolating the very people they are supposed to be serving. Just listen to the language we use: In such mental health systems we have "gatekeepers" whose job it is to "screen" and "divert" service users. In fact, we actually use the language of war in our work. For instance, we talk about sending "frontline staff" into the "field" to develop treatment "strategies" for "target populations."

Is there another alternative? Must we respond to the anguish and apathy of people with psychiatric disability with our own anguish and apathy? I think there is an alternative. The alternative to despair is hope. The alternative to apathy is care. Creating hope filled, care filled environments that nurture and invite growth and recovery is the alternative.

Remember the sea rose? During the cold of winter when all the world was frozen and there was no sign of spring, that seed just waited in the darkness. It just waited. It waited for the soil to thaw. It waited for the rains to come. When the earth was splintered with ice, that sea rose could not begin to grow. The environment around the sea rose had to change before that new life could emerge and come into being.

People with psychiatric disabilities are waiting just like that sea rose waited. We are waiting for our environments to change so that the person within us can emerge and grow.

Those of us who have given up are not to be abandoned as "hopeless cases." The truth is that at some point every single person who has been diagnosed with a mental illness passes through this time of anguish and apathy, even if only for a short while. Remember that giving up is a solution. Giving up is a way of surviving in environments which are desolate, oppressive places and which fail to nurture and support us. The task that faces us is to move from just surviving, to recovering. But in order to do this, the environments in which we are spending our time must change. I use the word environment to include, not just the physical environment, but also the human interactive environment that we call relationship.

From this perspective, rather than seeing us as unmotivated, apathetic, or hopeless cases, we can be understood as people who are waiting. We never know for sure but perhaps, just perhaps, there is a new life within a person just waiting to take root if a secure and nurturing soil is provided. This is the alternative to despair. This is the hopeful stance. Marie Balter expressed this hope when asked, "Do you think that everybody can get better?" She responded: "It's not up to us to decide if they can or can't. Just give everybody the chance to get better and then let them go at their own pace. And we have to be positive - supporting their desire to live better and not always insisting on their productivity as a measure of their success." (Balter 1987, p. 153).

So it is not our job to pass judgment on who will and will not recover from mental illness and the spirit breaking effects of poverty, stigma, dehumanization, degradation and learned helplessness. Rather, our job is to participate in a conspiracy of hope. It is our job to form a community of hope which surrounds people with psychiatric disabilities. It is our job to create rehabilitation environments that are charged with opportunities for self-improvement. It is our job to nurture our staff in their special vocations of hope. It is our job to ask people with psychiatric disabilities what it is they want and need in order to grow and then to provide them with good soil in which a new life can secure its roots and grow. And then, finally, it is our job to wait patiently, to sit with, to watch with wonder, and to witness with reverence the unfolding of another person's life.

That sounds good but how do we do it? I have some very concrete suggestions as to how to enter into a conspiracy of hope and build communities of hope around people who have lost hope.

First, we must be committed to changing the environments that people are being asked to grow in. We must recognize that real change can be quite uncomfortable and sometimes I worry we will content ourselves with superficial change. I worry about new and catchy words like consumer integration, empowerment, clubhouse models and partnership. It seems to me that over the decades we keep coming up with all kinds of trendy words and names to call each other. For instance, in the fifties it was the doctors and the patients. In the sixties it was the staff and the clients. In the seventies it was the providers and the consumers. In the eighties it was the staff and the members. Now in the nineties we have "shareholders" and the Managed Care Corporations (MCO's).

Yes, the names we call each other have certainly changed. But I would argue that the fundamental relationship between those labeled with mental illness and those who are not, has remained essentially unchanged. There is a wise old monk who lives in the Nova Nada community, out in Kemptville, Nova Scotia. His name is Fr. William MacNamara. When talking about our attempts to bring about change, he says: "It's like we keep rearranging the chairs on the deck of the Titanic but all we really achieve through this effort is a better view while going down." That's the big danger of simply using the newest program designs and politically correct language. If we're not careful, all this will amount to is rearranging the chairs on the deck of a sinking ship. Somebody has got to say, "Stop! Wait! Forget the catchy words. There's a big gaping hole in this boat we call the mental health system and we are all going down with it!"

You see, I would argue that until the fundamental relationship between people who have been psychiatrically labeled and those who have not changes, until the radical power imbalance between us is at least equalized, until our relationships are marked by true mutuality, until we stop using barbaric practices such as restraint and seclusion while trying to convince people that such torture is for their own good, and until we recognize the common ground of our shared humanity and stop the spirit breaking effects of dehumanization in the mental health system, then that gaping hole will continue to sink the best of our efforts.

The human-interactive environment of mental health programs and the community must change if people are going to move from just surviving to the journey of recovery. We must stop exercising "power over" the people we work with. This only produces unnecessary dependency and learned helplessness. Instead, we must join with people like Dr. Jean Baker Miller (1976) and other scholars at the Stone Center at Wellesley College. Following their lead, we must begin to think in terms of having "power with" or "creating power together" rather than having "power and control over" the people we work with. In this way traditional power relationships, which have historically been so oppressive for people with psychiatric disabilities, will change. Specifically, this means we must stop using the phrase, "I judge this to be in the client's best interest" and instead ask people what they want for their own lives and provide them with the skills and support to achieve it.

We must commit ourselves to removing environmental barriers which block people's efforts towards recovery and which keep us locked in a mode of just trying to survive. For instance, I would suggest examining the following questions:

1. Are the people we work with overmedicated? Very often the apathy, lack of motivation, and indifference we observe is an effect of neuroleptics. Are we teaching consumer/survivors about this drug effect and helping them effectively advocate for medication changes and/or reductions? The multinational drug industry is literally making a fortune through the sales of these drugs. Our priority is not to increase their quarterly profit margins. Our priority is to support people in their recovery process. It is not possible to actively participate in our own recovery process when we are in state of drug induced mental Parkinsonism, apathy and indifference.

2. Are consumer/survivors in both community based and hospital programs involved in evaluating staff work performance? Who better knows how effective a staff person is than those receiving services from that staff person? Additionally, are we providing consumer survivors with the skills training and support to conduct such evaluations?

3. Are program participants and hospital inpatients receiving peer skills training on how to participate in and effectively get what they want from a treatment team? Are we allowed to sit through the entire treatment-planning meeting and are staff committed to speaking in plain English so we can understand the conversation? Are there peer advocates who are available to come to the treatment planning meetings with us? Are there opportunities to meet prior to the team meeting in order to strategize what we want to get out of the meeting and how to go about presenting our ideas? Is there time to roleplay speaking up and dealing with questions prior to the treatment planning meeting?

4. Are there separate toilets or eating space for staff and program participants? If there are, they should be eliminated. This is called segregation and creates second-class citizens.

5. Who can use the phones? Who makes what decisions? Who has the real power in this program? Information is power and having access to information is empowering. What are the barriers to getting information in the program?

6. Do we understand that people with psychiatric disabilities possess valuable knowledge and expertise as a result of their experience? Do we nurture this important human resource? Are peer run, mutual help groups available? Are we actively seeking to hire people with psychiatric disabilities and to provide the supports and accommodation they may request?

7. Have we created environments in which it is possible for staff people to be human beings with human hearts? Do we offer supervision or staff surveillance? Perhaps we could help create more humanized work environments if we sought to view working with people as a journey in which we both move and are moved by the people we seek to serve. Perhaps we could offer our workers what Jean Vanier (1988) calls “accompaniment.” Accompaniment means offering to walk with our staff as they make that sometimes painful, sometimes joyous journey of the heart we call the “direct care relationship.” Directly caring. Ah! Now there’s true change.

8. Do we work in a system which rewards passivity, obedience and compliance? Is compliance seen as a desirable outcome? As a friend who is a consumer/survivor told me, “Tell those case managers that they have it all wrong. Tell them to stop saying that compliance is the road to independence.” And indeed, compliance is not the road to independence. Learning to become self-determining is an outcome that is indicative of environments that support opportunities for recovery and empowerment.

9. Have we embraced the concept of the “dignity of risk” and the “right to failure?” “Chronically normal people” (CNP’s!), or people who have not been psychiatrically labeled, are allowed to make dumb, uninsightful decisions all the time in their lives. My favorite example is Elizabeth Taylor who just got her eighth divorce. We might say, “She lacks insight! She is failing to learn from past experience!” However, when she embarks on marriage #9, no SWAT team of nurses with Prolixin injections will descend upon her “in her best interest.” But just imagine if a person with a psychiatric disability were to announce to their treatment team that they were about to get married for the 9th time! People learn, and sometimes don’t learn from failures. We must be careful to distinguish between a person making (from our perspective) a dumb or self-defeating choice, and a person who is truly at risk.

10. Are there opportunities within the mental health system for people to truly improve their lives? Are there a range of affordable, normal housing situations from which people can choose a place to live? Is there work available? A person who just recently went back to work after many years of hospitalization said to me, “What’s all this talk about empowerment? I can tell you the definition of empowerment: “It’s a decent paycheck at the end of the week.”

These are just some suggestions about how to create environments in which it is possible for people to grow.

Then, as we build these hope filled environments, we must recognize that people with psychiatric disabilities do not “get rehabilitated” in the same sense that cars “get tuned up” (Deegan 1988). We are not passive objects which professionals are responsible for “rehabilitating.” Many of us find this connotation of the word rehabilitation to be oppressive. We are not objects to be acted on. Rather we are fully human subjects who can act, and in acting can change our situation.

We are not objects to be fixed. Such a connotation robs us of our own sense of autonomy and self determination. It places responsibility in the wrong place. It perpetuates the myth that we are not and cannot be responsible for our own lives, decisions and choices.

The truth is that nobody has the power to rehabilitate anybody else’s life. This is clearly evidenced in the fact that we can make the finest and most advanced rehabilitation technologies and programs available to people with disabilities and still fail to help them. As it is said, “You can lead a horse to water but you can’t make it drink.” Something more than just good services is needed. That “something more” is what I call recovery.

The concept of recovery differs from that of rehabilitation in as much as it emphasizes that people are responsible for their own lives and that we can take a stand toward our disability and what is distressing to us. We need not be passive victims. We can become responsible agents in our own recovery process. That is why it is so dangerous to reduce a person to being an illness. If we insist that a person learn to say, “I am a schizophrenic,” then in essence we are insisting that the person equate their personhood with illness. Through such a dehumanizing reduction the disease takes on what is called a “master status” in terms of identity. Thus, when a person learns to believe “I am a schizophrenic,” when their identity is synonymous with a disease, then there is no one left inside to take on the enormous work of recovery. That is why we must always help people to use person first language i.e., I am a person labeled with schizophrenia; I am a person diagnosed with mental illness, etc. Person first language always reminds us that first and foremost we are human beings who can take a stand toward what is distressing to us.

Each person’s journey of recovery is unique. Indeed, each of us must discover for ourselves what promotes our recovery and what does not. Many of us find that intermittent or ongoing treatment is an important part of our recovery process. However, when in recovery we learn to use treatment as one tool among other, equally important tools. Thus, we learn to use medications rather than to simply take medications. We learn to use the hospital rather than simply going to the hospital. This is the active stance that is the hallmark of the recovery process.

For some of us who have historically used or abused drugs of alcohol, or who have grown up in alcoholic families, or who have survived childhood sexual, emotional and/or physical abuse, participation in various self help and twelve step programs may play a vital role in our recovery process.

Many of us find that social and vocational rehabilitation programs offer us unique opportunities and we use these services as part of our recovery process. Most of us find that developing friendships based on love and mutual respect is very important to our recovery. Of course, permanent, affordable and fully integrated housing is fundamental to the recovery process. Many of us find that participating in a spiritual community of our choice gives us the strength and hope to keep working hard in our recovery process.

Finally, many of us find it important to participate in consumer/survivor run support networks and advocacy groups in an effort to help change the mental health system, to establish alternatives to traditional services, to make government aware of our needs, to fight for our full civil rights and to collectively struggle for social justice. In fact, I use the term recovery to refer not only to the process of recovering from mental illness, but also to refer to recovering from the effects of poverty, second class citizenship, internalized stigma, abuse and trauma sustained at the hands of some “helping professionals”, and the spirit breaking effects of the mental health system. Indeed, self help and social action cannot be arbitrarily separated. At some point, helping ourselves includes joining together as a group to fight the injustices that devalue us and keep us in the position of second-class citizens.

Recovery does not refer to an end product or result. It does not mean that one is "cured." In fact, recovery is marked by an ever-deepening acceptance of our limitations. But now, rather than being an occasion for despair, we find that our personal limitations are the ground from which spring our own unique possibilities. This is the paradox of recovery i.e., that in accepting what we cannot do or be, we begin to discover who we can be and what we can do. Thus, recovery is a process. It is a way of life. It is an attitude and a way of approaching the day's challenges. It is not a perfectly linear process. Like the sea rose, recovery has its seasons, its time of downward growth into the darkness to secure new roots and then the times of breaking out into the sunlight. But most of all recovery is a slow, deliberate process that occurs by poking through one little grain of sand at a time.

As the sea rose teaches us, the work of growth is slow and difficult but the result is beautiful and wondrous. We have chosen very difficult work. Sometimes I think we are a little weird for choosing this line of work. I mean, computers don't ask that we grow and the pay is certainly better. But we stick with this work and are faithful to it. Why? Because we are part of a conspiracy of hope and we see in the face of each person with a psychiatric disability a life that is just waiting for good soil in which to grow. We are committed to creating that good soil. And so I celebrate you. I celebrate the strong and fiercely tenacious spirit of people with psychiatric disabilities. I celebrate the person within each of us. I celebrate hope. I celebrate our conspiracy. And I think we all deserve a round of applause. Thank you!

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PROJECT RETURN
PEER SUPPORT NETWORK
Taking charge together!

A NOTE

I, Joana Arcangel, am a peer with lived experience – meaning I identify with mental health recovery. At the Hacienda of Hope and through our organization, Project Return Peer Support Network, we utilize these experiences and focus on strength-building through a person-centered approach to connect with and help others in their journey.

I cannot fully express my gratitude for the many leaders and other peers who've paid the way for mental health education and empowerment. This includes organizations that instill so much hope in others, such as Project Return Peer Support Network, where I have found a sense of belonging and my calling as a peer professional, and generous individuals like Mary Ellen Copeland, who has given many individuals the support, confidence and tools to take charge of their own recovery through creating the Wellness Recovery Action Plan.

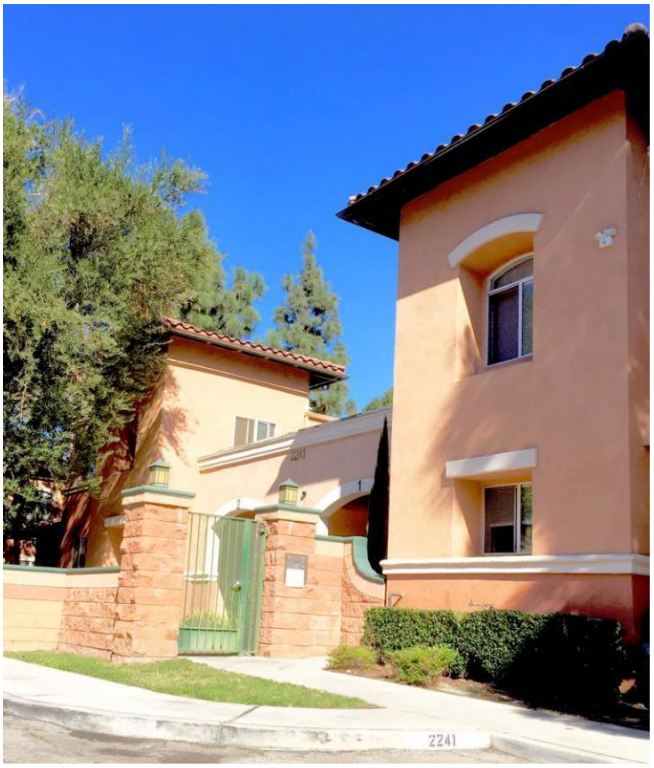
I am open about my mental illness not because I don't care about what people think. In fact, I care a lot. I care to open the conversation, I care to open hearts, open minds, open doors. I have faced trauma as a child, developed what has been a very debilitating phobia and my self-destruction was a security blanket that I held close for so long though it only suffocated me. Throughout my life, I had hope, but so many times it was just a flickering light in the cold darkness. That hope, no matter how small it can become or how much it waivers, has been the heart of my resilience.

Being a mental health advocate isn't just a job to me. It is a part of who I am. I look at the Department of Mental Health symbol – Hope, Recovery and Wellness – as a wheel. I am grateful I've had people to ask for directions when I felt lost, people who were my designated drivers, people who kept me company during long exhausting roads. However, the direction I'm headed has always been up to me. I am the ultimate driver of my recovery and although it may not always be full of beautiful sceneries and sunshine, I know it will always be mine to take.

ABOUT PROJECT RETURN PEER SUPPORT NETWORK & THE HACIENDA OF HOPE

PRPSN has evolved and expanded in its 35 years of operation. It was California's first staff-facilitated peer support program for people with mental illness. In 2015, PRPSN was recognized by Los Angeles County Department of Mental Health as its own legal entity and expanded its breadth and depth as a contract provider to include: IMD step-down, peer support/peer counseling/peer mentoring services, alternative crisis support, bridging and support services, workforce training and development, wellness centers/client run centers, and innovation services.

One of Project Return's leaders, Associate Director Angelica Garcia, is a Copeland Center certified WRAP facilitator.



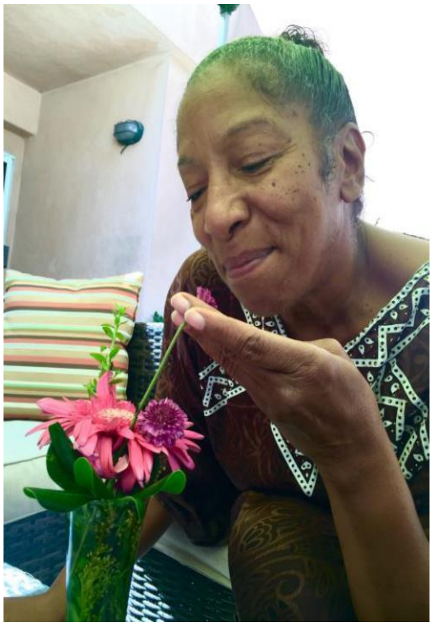
"As a person with a lived experience and working professional in the mental health field, I have found that utilizing WRAP for the last 9 years has been very effective in maintaining my own wellness. Given the functions of fast paced [daily agenda], I have found that having a plan in place reassures me that even if I start noticing signs that are uncomfortable, I can actually take action before they progress. I have established a support system that understands my needs when things might now be going so well. Being a WRAP Facilitator helps me educate others on a system management tool that has been very effective for many of us."

Hacienda of Hope opened its doors in 2013 as one the first Peer-Run Respite Care Homes in Los Angeles County. Funded by the Los Angeles County Department of Mental Health, Hacienda of Hope was developed to meet individuals' need for respite in times of crisis and distress when there is no clinical danger. This provides an opportunity to develop a wellness and recovery plan, along with other practical tools, to promote a positive reinforcement of values, relationships, health and life skills that would not necessarily be available in a psychiatric setting.

Annette Scott was a former social worker who identified as a peer and came to the Hacienda of Hope as a guest. She was able to work on her recovery through the power of peer support and tools like WRAP. ***"Being a former social worker has brought me full circled with my profession. Now, I am in need of services… I have found respite. The Hacienda of Hope is a place where you can rest, heal and redirect or regain insights for a healthier lifestyle. With my stay at the Hacienda of Hope, I have gained epiphanies and empowering reflective moments… I can empower others with life skills I have regained at the Hacienda of Hope."***

Our team is staffed with people who identify as peers – those who have found recovery from the stigma, isolation and hopelessness associated with mental illness. We share lived experience to instill hope and provide guidance and support to those who are facing difficulties that challenge a person's mental health and wellness.

At the Hacienda of Hope, we utilize our organizational core values – Hope, Empowerment, Recovery, Mutuality and Integrity – to find common ground with our guests and visitors to promote a safe, inclusive and welcoming environment. We promote our peer-run respite care home as a means to eliminate stigma surrounding mental illness, provide alternative options to hospitalization which can decrease homelessness, help a person to rediscover their strengths, needs, dreams and aspirations, and encourage independence and personal responsibility in one's recovery and life.



Gregory Park, a former Hacienda of Hope guest, wrote about his experience in a letter of gratitude to the staff: ***"When I first arrived here, I did not know what to expect. [My days were] filled with a lot of traumatic, dramatic and stressful situations… During my time here, I found my spark that makes me who I am. Thank you for making this experience truly a memorable one. I was able to achieve many goals and begin plans to better my life."***

Our guests typically stay for 3-5 days. During their stay, guests receive support with activities of daily living, attend peer-run support groups, participate in extracurricular and recreational activities and are linked to outside services and community support.

We base our program, including our peer-run groups, on SAMHSA's Eight Dimensions of Wellness (Emotional, Social, Physical, Intellectual, Spiritual, Financial, Occupational and Environmental Wellness). Our groups include: Walking Meditation, WRAP (Wellness Recovery Action Plan), Music, Spiritual Enlightenment (discussions on spirituality), Your Voice (based on practices by the Hearing Voices Network) and more. Our support groups are facilitated by staff, interns, and volunteers and are open not only to our guests, but to adults who would like to participate.

Michol Loeffler is a peer specialist staff member who facilitates our WRAP group at the Hacienda of Hope. She shares her personal experience with mental health challenges, how she found WRAP and how she now helps others take charge of their recovery. ***"I became a WRAP facilitator in 2008 and have been facilitating WRAP ever since. I share my journey with guests as an example of what recovery can look like. The tools and concepts of WRAP are helpful to my interaction with guests and visitors. WRAP has shown me that others have the freedom to create their own wellness, just as I have. Because of that, I'm able to guide another person through their journey of wellness, not mine. I believe that this is what WRAP is all about."***

We are located in the Century Villages at Cabrillo in Long Beach, which is an inclusive community of programs that provide a variety of services to various populations, including veterans, low-income families and individuals who deal with mental health issues. At CVC, we often work together and use collaborative efforts to provide services to our members.

Grace Yim, a student at California State University, Dominguez Hills and intern at CVC, was able to experience building her own WRAP. ***"As an occupational therapy student who wants to specialize in mental health, I am always eager to learn about evidence-based practices that help people with mental health conditions recover and lead meaningful lives. What is most inspiring about WRAP is that it gives the individual control over his/her illness experience and recovery process. This resource speaks to a vision of health care that empowers clients and facilitates the process of shaping their future possibilities."***

PRPSN's CORE VALUES

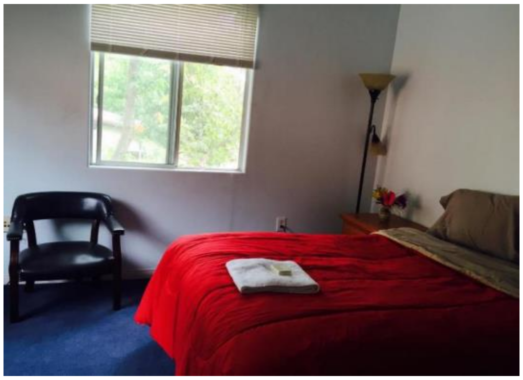
Hope: We hold the belief that things can get better. We never give up and we educate people that no matter how bad things seem, if you take one step at a time, things will change for the better.

Empowerment: We enhance personal growth and inner strength while motivating, inspiring and guiding ourselves and peers into action. We encourage others to reach their full potential by allowing them to find their internal strengths.

Recovery: We believe that individuals who have suffered from mental health challenges can go on to lead successful fulfilling lives. We see individuals grow when they seek out information and utilize the resources offered. Individuals regain their sense of self by taking control of the things which previously seemed beyond their control.

Mutuality: Regardless of our job title, we are all equal and thus treat each other with dignity and respect. We respect the validity of every individual's experiences, thoughts, opinions, and feelings, even if they are different than our own.

Integrity: We practice honesty at all times – personally and professionally. We operate using moral judgement, character and leadership values and do things in a fashion of respect and professionalism.



Community Resources

22. p. 81: Identify and research three (3) resources that are available in your community. Gather information (website, brochure, flyer, etc.) and be prepared to share these resources with the class.