yale program for recovery and community health

Person-Centered Behavioral Health Interventions: Innovative Approaches

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What I hope to cover

- Function and brief history of psychosocial interventions
- Current state-of-the-art and future directions
- Eliminating discrimination and restoring personhood as preconditions for treatment and rehabilitation to be effective

Functions of Psychological and Social Interventions

- Treatment
- Rehabilitation
  - Skill Development
  - Tools and Environmental Accommodations

Brief History of Clinical Care

- Development and use of therapeutic communities in hospitals
- Deinstitutionalization to the combination of "thorazine and therapy"
- Discrediting of investigative (i.e., psychodynamic) forms of psychotherapy, resulting in …
- Supportive psychotherapy and case management
- Disorder-specific cognitive-behavioral interventions

Brief History of Psychiatric Rehabilitation

Fountain House, vocational rehabilitation, and residential alternatives arose with deinstitutionalization.

By the 1970s, de-institutionalization was being considered a 'failed policy' for two main reasons:

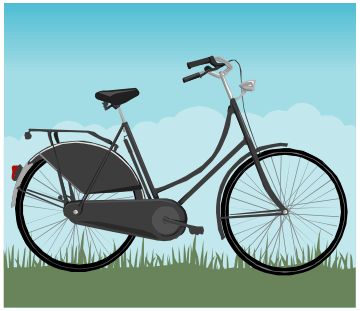
Funding had never been provided to create the community-based supports people needed to live meaningful lives in the community.

The interventions that had been developed were not effective in affording people lives beyond the mental health system.

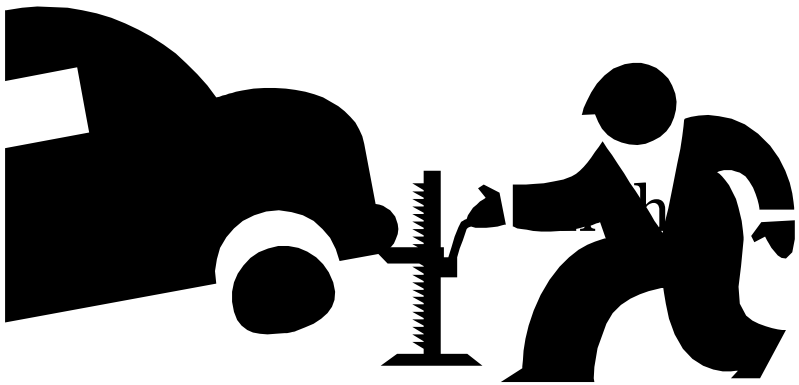
(one study suggested that it took an average of 43 years to get a job)

The Move to Community-Based Work

Assertive community treatment developed in the 1960-1970s.



- Based on several lessons:
  - Many people still needed support
  - Skills did not generalize from hospital or classroom
  - Learning requires <u>modeling</u>
  - With modeling and support, people could hope to live a full life in the community.



Current State-of-the-Art

- Cognitive-behavioral psychotherapies developed since the 1990s have targeted positive symptoms
- Cognitive remediation or retraining has targeted neurocognitive deficits
- Supported housing, employment, education, socialization, parenting, and spirituality offer access to full, meaningful lives
- Peer support has targeted engagement in both clinical services and self-care, with a focus on instilling hope and activating and role modeling self-management and recovery

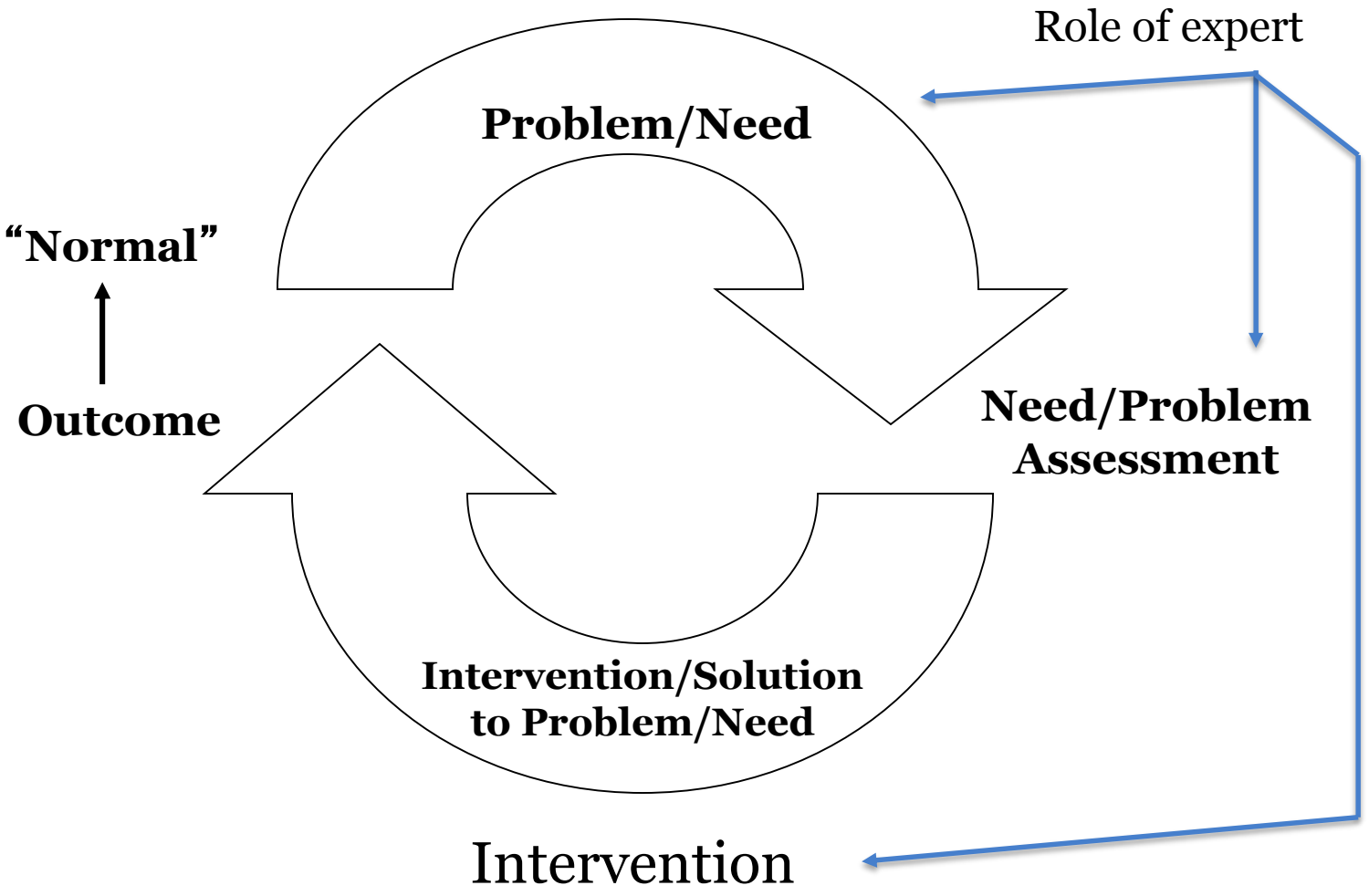
Current Directions

- Implementing person-centered and collaborative models of care (as mandated in the ACA; CMS)
- Developing new, disorder-specific psychotherapies that incorporate lessons learned (e.g., from Open Dialogue, Hearing Voices Movement) and go beyond adaptation to illness
- Shifting goal posts of care from “recovery” to full citizenship in welcoming communities (i.e., social determinants of health; social inclusion – Trieste, Lille, Columbia, New Haven)

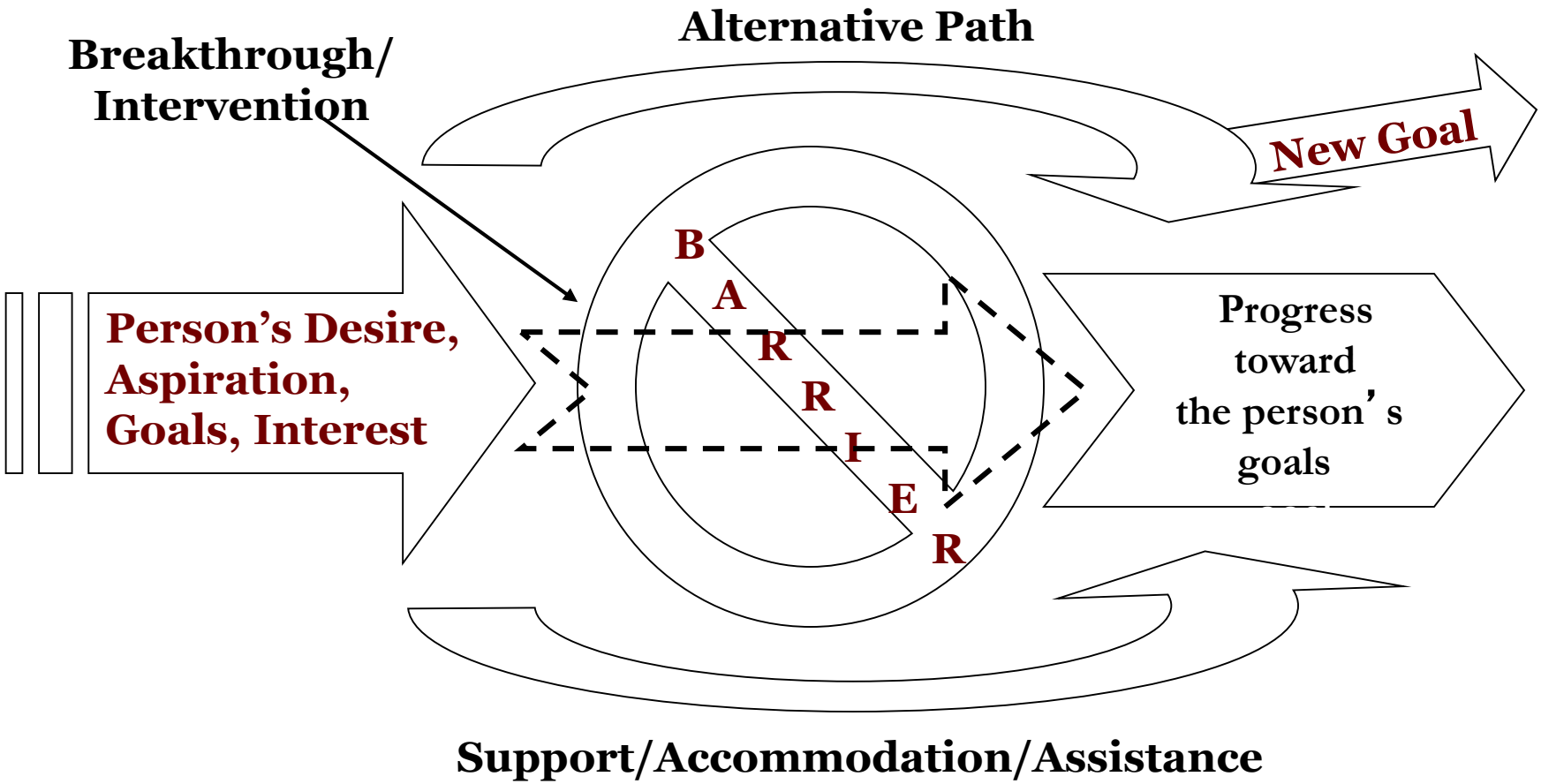
Ways to change practice

- Move from treatment or service planning to recovery planning
- Move from viewing practitioner as active expert and client as passive recipient to person as driver of his or her own recovery process
- Reframe illness, symptoms, and impairments from focus of care to ***barriers*** to the person's pursuit of a life worth living (who we are is based on what we do – Sen)

Deficit-Based Model

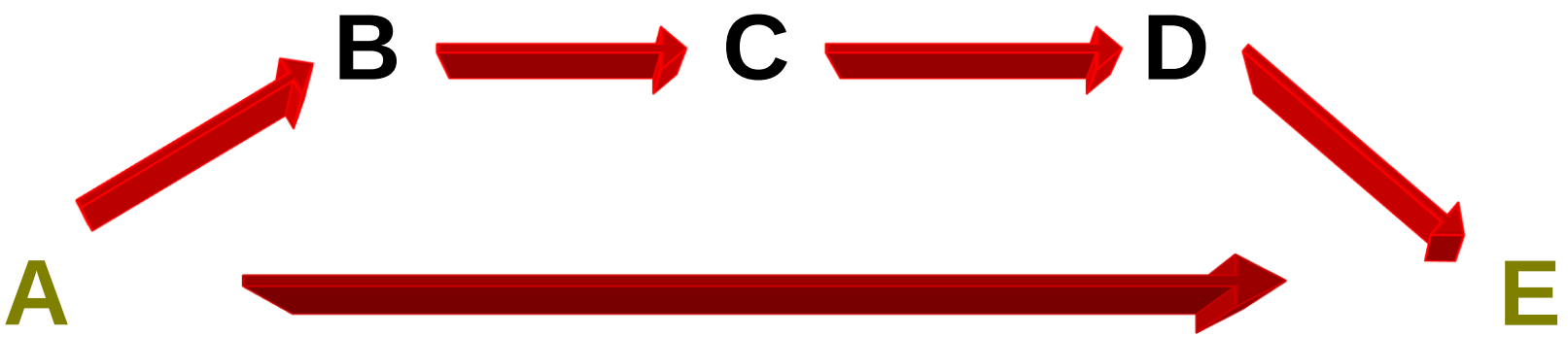


Strength-Based Model



The Recovery Plan as a Road Map

Provides hope by breaking a seemingly overwhelming journey into manageable steps for both the provider and the person served



"life is a journey…not a destination"

Care Focus Comparison

Traditional		Recovery
Stability	→	Hope for future
Compliance	→	Choice
Control	→	Partnership
Focus on deficits	→	Focus on strengths
Low expectations	→	High expectations

Traditional		Recovery
Learned helplessness	→	Active participation
Protection from failure	→	Risk is supported
Stabilization is the desired result	→	Meaningful life is the desired result

Leads to Shifts in Process/Meeting

- Best-practice person-centered care/recovery planning is about much more than the treatment plan document itself!

- It involves significant shifts in how we partner with service recipients to create a plan that becomes a road-map to recovery – within the hospital and beyond

Role of the Person in Recovery

- The individual in recovery and family are encouraged to participate to the maximum extent possible in all planning meetings
- Level of involvement and self-direction varies based on personal preference as well as level of interference from active symptoms
- Many individuals and families benefit from education and preparation in order to overcome fears or other factors which might influence their participation

Strength-Based Ways of Knowing

- Can take time and a trusting relationship; plans must be living documents
- Is carried out as a reciprocal dialogue
- Explores strengths beyond the individual; expands what is valued as a "strength"
- Explores what has worked for the individual (or peers) in the past, e.g., WRAP strategies
- Is creative in HOW questions are asked
- Incorporates strength-based language

Remember the Power of Language

Glass Half Empty

- Resistant/in denial
- Non-compliant

- "Frequent flier"
- Problems
- Manipulative
- Acting out
- "A Bipolar"

Glass Half Full

- Pre-contemplative
- Prefers alternative approaches
- High user of services
- Needs/challenges
- Resourceful
- Person disagrees
- A person diagnosed with…

Shifts in Process

- Recognize the range of contributors to the process
  - preferred outpatient supporters; peers; natural Circles of Support
- Value community inclusion
  - What skills are actively being built while in hospital?
  - What will daily routine look like after discharge?
  - Post crisis plan – what does it involve in addition to treatment?
- Understand and support right to self-determination
  - role of advance directives, personal preferences plans

And Shifts in the Written Plan

INDIVIDUAL's LIFE GOAL
as Defined by Person

CURRENT TREATMENT GOAL /GOAL DESCRIPTION
What Person Wants/Needs to Achieve

Strengths/Assets to Draw Upon	Barriers To Achieving Goals

Short-Term Objective
- Behavioral
- Achievable
- Measurable

Services & Other Action Steps
- Professional Services (Clinical/Rehab/Nursing, etc.)
- Action Steps by Person in Recovery
- Roles/Actions by Natural Supporters

But what if the person has no goals?

Reasons for not having goals

- Has the person become demoralized over time, due to repetitive experiences of failures and losses that have been due to mental illness, or discrimination, or a combination of both? Has the person lost hope as a result?
- Has the person become socialized into a mental health system that has not cared about his or her aspirations or interests in the past? Is what you are seeing the result of "learned helplessness," rather than a lack of goals?
- Might the person be so impoverished that he or she does not have the means to pursue goals?
- Has the person become afraid of taking risks, either because he or she might fail or be perceived as failing by others, or because either success or failure might precipitate a relapse or setback?
- Could this person have a co-occurring depression?
- Have you made the effort to earn the person's trust so that he or she would feel comfortable enough to share such personal information with you?
- Is the person experiencing signs or symptoms of a mental illness that might pose barriers to his or her participation in interesting or enjoyable activities?

Top 10 Reasons to do Something rather than Nothing

For participation to be meaningful, it should offer the person access to opportunities…

- For becoming better at something and/or accomplishment
- For affiliation and/or connection with others
- For affinity (interest)
- For exercising agency and/or authority
- For experiencing pleasure and/or joy
- For connecting to something larger than oneself
- For reflection, quietude, and/or self-expression
- For caring for and being good to one's self
- For caring for others (and being cared for by others)
- For prospering

Conversation Tips

- A helpful conversational structure might be to begin with talking about the person's everyday activities in the present, then move to reflecting on his or her ways of participating in everyday activities from the past that were different, and then to what the person might like to add or change in the future if it were to become possible.

- Consider it a conversation, not an interview, that may possibly occur across several encounters or over time, rather than as a "checklist" of topics to be covered or completed.

Starting Points

- What are your days like at the moment? How do you spend your days?
  - What kinds of activities are you involved in?
  - Who do you spend time with? What kinds of activities do you do together?
- What kinds of activities did you used to do?
  - What have you done that gave you a sense of enjoyment or achievement?
  - What's been helpful in getting to do these things?
- What is important to you in your life now?
- What would you like to be doing in the future if it were to become possible?
- What could be the issues or obstacles to overcome? And what might help to make it happen?

Eliminating discrimination and restoring personhood

- The most disabling and terrifying aspect of psychosis described by persons with schizophrenia is the loss of a sense of self, the loss of a sense of being a person

- This loss is compounded by the discrimination faced by persons with psychosis on a day-to-day basis through various macro and micro-aggressions, inside of the mental health system as well as outside

- As a result, regaining a sense of self provide be a necessary foundation for being able to use other psychosocial interventions effectively

First: Loss of Self

"… And then something odd happens. My awareness … instantly grows fuzzy. Or wobbly. I think I am dissolving. I feel—my mind feels—like a sand castle with all the sand sliding away in the receding surf… This experience is much harder, and weirder, to describe than extreme fear or terror … Explaining what I've come to call 'disorganization' is a different challenge altogether. Consciousness gradually loses its coherence. One's center gives way. The center cannot hold. The'me'becomes a haze, and the solid center from which one experiences reality breaks up like a bad radio signal. There is no longer a sturdy vantage point from which to look out, take things in, assess what's happening. No core holds things together, providing the lens through which to see the world, to make judgments and comprehend risk. Random moments of time follow one another. Sights, sounds, thoughts, and feelings don't go together. No organizing principle takes successive moments in time and puts them together in a coherent way from which sense can be made"

-- Elyn Saks, 2007

Disruption of agency/intentionality

- If I can't direct my own attention …
- If I no longer experience my actions as stemming from me …
- If I can't hold thoughts together or remember from one minute to the next …
- If even my thoughts seem to come from someone or somewhere else …

And then, on top of that,

- If other people act as if I am not here …
- If other people do things to me without my permission or consent …
- If other people make decisions for me and about me without asking me …
- If other people tell me that I'll never get better …
- If other people act as if I have nothing to offer …
- If other people no longer treat me as a person …

…then perhaps I'll come to believe that myself

"I felt like a nobody nowhere"

-- Weingarten

Two Main Targets

- Carry "surrogate" hope (Deegan) until the person can muster his or her own (micro-affirmations)

- Instill hope in the person through access to opportunities, pleasures, and successes (micro-actions)

Micro-affirmations

Common courtesy works because it's common; it's something every human being gets just because they're human. Things like saying 'excuse me' when you reach over someone to reach for a piece of paper, like saying 'God bless you' when someone sneezes, things like asking you if you'd like some water when you get up to get some for yourself. It's basic, but it means so much to someone who's been treated like an un-human for decades. It's basic, and it may seem trivial to you, but to people like me, it's water to a dying parched husk of a person. Interactions like the[se] … have more positive impact on the consumer than any elaborate treatment plan ever could. -- Amy

Micro-actions

A sense of self is the basic… Now, I have a very fleeting, very fragile sense of self. I am thwarted by visual disturbances, auditory hallucinations, tactile flashbacks, waves of intense emotion, and paranoia. I get caught up in me easily, where I literally can't see what's in front of me. A sense of self gives one the right to speak, it fuels the indignation required to speak… A sense of self makes all other behaviors possible; without a self, nothing can happen. This is why schizophrenia is so debilitating. -- Amy

Modeling self-respect and how to respect others involves active listening and improv; you must be ready at any moment to demonstrate respect. Little moments pop up … where the consumer's weakness in self-esteem become apparent, and your job … is to pay attention to those maybe quiet holes and fill them. Self-esteem doesn't point out where it's been hurt, and that's why listening is so important. You have to listen for the holes in self-esteem. Each person has a personality, and each person has a history, so the remedy for each hole may be a bit different, so you'll have to think quickly on your feet and sort of craft a makeshift self-esteem for your client. It's not dissimilar to a crisis triage in that you are working quickly and efficiently to save a person's life. Self-esteem is critical to an individual's sense of self, to an individual's sense of efficacy, to a person's recovery. I didn't enter recovery until someone else thought I was worth recovery, until someone else loved me. I didn't think I was worth recovery until someone else did. -- Amy

How does this change practice?

Many existing treatments presume either:

- That the person has to be restored to personhood by others before taking steps toward recovery him or herself (e.g., involuntary treatment), or
- That the person has remained a person and can take responsibility for his or her self-care and rehabilitation (e.g., skills training)

Both assumptions are problematic

Current Practices

- Cognitive-behavioral psychotherapy assumes a collaborative relationship with the client
- Medication adherence requires a person to take responsibility for self-care
- Cognitive remediation involves a working alliance
- Psychiatric rehabilitation requires a minimal amount of confidence in one's own agency and efficacy

And yet

"Once a person comes to believe that he or she is an illness, there is no one left inside to take a stand toward the illness. Once you and the illness become one, then there is no one left inside of you to take on the work of recovering, of healing, of rebuilding the life you want to live" (Deegan, 1993, p. 9).

How do you help a person 'relearn' to be a person?

- First and foremost, by treating them as if they are one already and always have been (through micro-affirmations)
- By not perpetuating the culture and practices which contributed to their losing their sense of being a person to begin with (avoiding micro-aggressions)
- By not making decisions for them, doing things to them, or doing things for them without asking (or at least informing or explaining what you are doing and why)

It is what Amy prayed for all these years – not to be laughed at, not to be dismissed, to be listened to and taken seriously. I can't believe it. There are people on this planet that will listen to Amy. Wow. It makes me cry. It makes me cry. I cry because I waited a long time for this. I waited alone. I waited just me, cheering me on, saying, 'Hold on Amy, hold on. One day somebody will see you.' And then here is it. Here you are… It was well worth waiting for, at the end of the rainbow … sits a pot of gold. I feel like my soul is sputtering, is gasping, because it's been not breathing for a long, long time, and you … are performing CPR, or blowing air into lungs long dead, lungs long dead that are only now gasping for air because I believed, because though I was dead, my mind stayed alive, and I sat up in there alone, like a magician, I believed, I turned coal into gold, told myself it felt good to be dead, it felt good to be lonely. It did not. I only lied to keep hope alive, so that if anyone ever came along and noticed I needed oxygen, they would blow some into my lungs so I could breathe again on my own. -- Amy

And then …

- By noticing the decisions they are making and the things they are doing as indicators of their remaining personhood.
- By finding out where their remaining passion or interests, their sense of meaning or purpose, and their pleasures have survived.
- By encouraging and supporting their sense of agency, even at the most micro of levels (e.g., getting out of bed in the morning).

What this form of recovery looks like

- Opening a bank account
- Not having to eat a hamburger alone
- Buying cards and presents for family and friends
- Making meaningful contributions to the lives of others ("giving back")
- Working, learning, loving, and playing like everyone else

Is this cure? No.

"Mental illnesses are highly disabling, and, as recent reviews have emphasized, our science has not come even close to being able to cure or prevent them. Learning to live better in the face of mental illness doesn't alter that reality."

-- Dickerson (2006)

But does it matter? Yes.

"From the perspective of the person with the disorder, [Dickerson] has it backward. It is especially when the illness is most severe, and because we do not yet have a cure, that people who have these disabling disorders have no choice but to live in the face of them. This is the reality that takes priority in recovery-oriented care."

-- Davidson, O' Connell & Tondora (2006)

In the end …

Here once again the memorable lips, unique and like yours.

I am this groping intensity that is a soul.

I have got near to happiness and have stood in the shadow of suffering.

I have crossed the sea.

I have known many lands; I have seen one woman and two or three men.

I have loved a girl who was fair and proud, with a Spanish quietness.

I have seen the city's edge, an endless sprawl where the sun goes down tirelessly, over and over.

I have relished many words.

I believe deeply that this is all and that I will neither see nor accomplish new things.

I believe that my days and my nights, in their poverty and their riches, are the equal of God's and of all men's.

-- Jorge Luis Borges, from *Fervor de Buenos Aires*, 1923 (1979, p. 43)