

Putting Recovery into Practice

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yale
program
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What I hope to cover

- How mental health isn't "just" health care
- The importance of restoring personhood as a foundation for recovery
- The 'technologies' that are being developed to promote community living
- The best we can hope for (for now)

What does being in recovery involve?

- The same things that help other people adapt to and live satisfying lives in the face of other chronic illnesses or disabilities
- These include:
 - Social support (being accepted and valued as a worthwhile and contributing person vs. patient)
 - Sense of personal agency and self-efficacy
 - Internal locus of control
 - Accurate and accessible information on self-care

A Major Difference

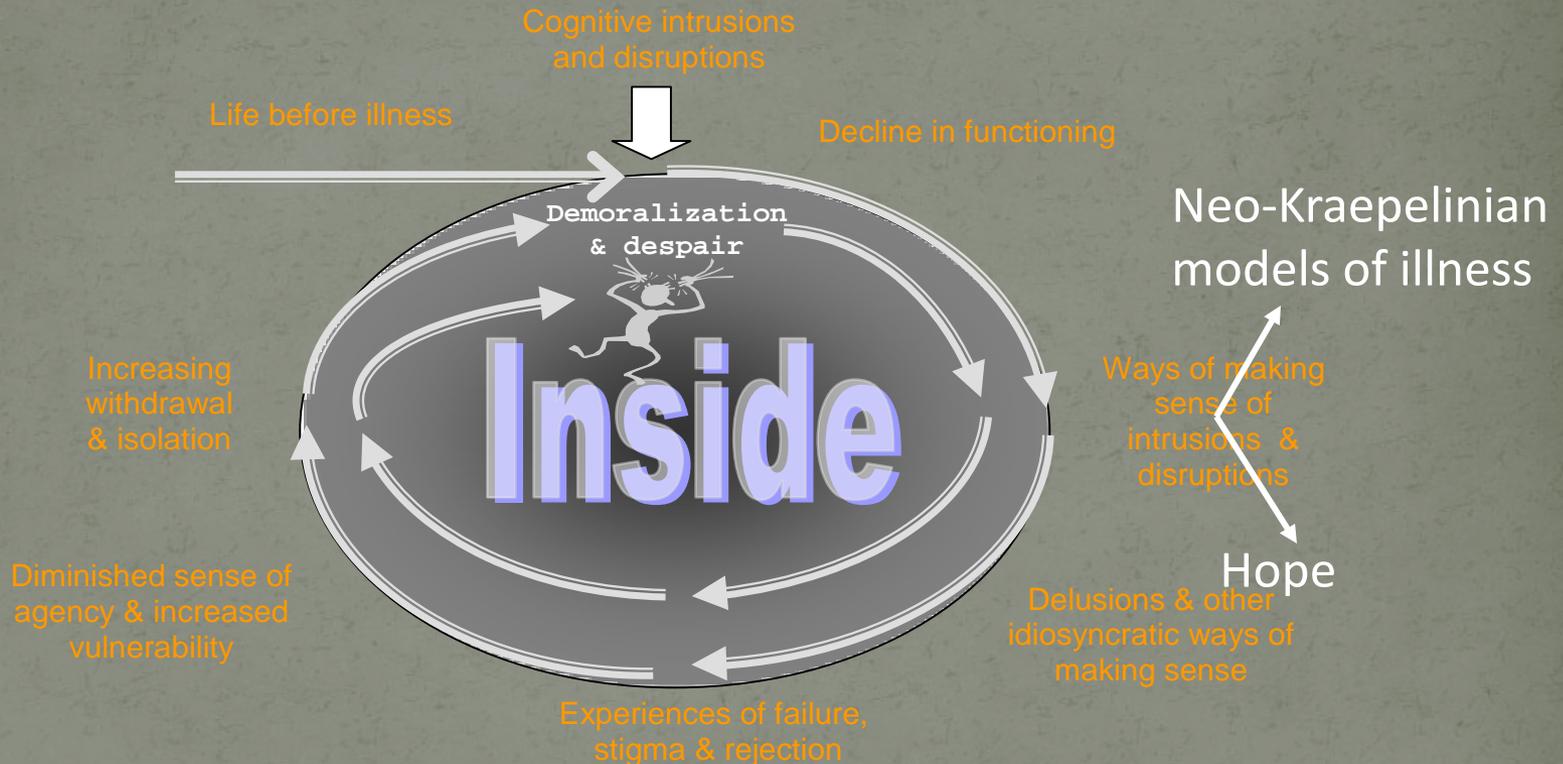
(why mental health care isn't "just" healthcare)

- But to have access to these resources, people first may have to regain a sense of themselves as worthwhile and effective human beings who are more than their illnesses
- Both because of the nature of the illness and because of the treatment they have received
- This becomes the first focus of care

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. And it’s all taking place in slow motion.” -- Elyn Saks, 2007

What has been our role in response?



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 ...

I become vulnerable to



the Tinkerbell issue



Tinkerbell

Stigma, discrimination
& messages of hopelessness

Contributing
person with
psychiatric
disability

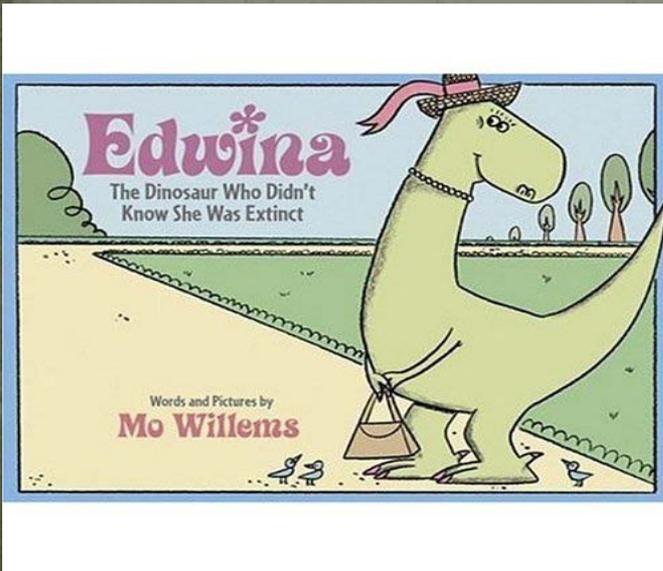
to

Contributing
citizen & visible
role model

Hope, determination &
encouraging support

—or—

Edwina



Basic tasks of being in recovery: (What do the Edwinas do?)

- Relearn how to be a person (an “I”)
- Make sense of illness experiences and learn how to live with them
- Maintain or regain a sense of belonging and personal worth
- Maintain or regain hope and the determination to have a better life
- Have opportunities to develop and exercise an effective sense of social agency by ...
 - Taking risks to reconstruct a sense of self and a safe, dignified, and meaningful life within the limitations imposed by the disability
 - Experiencing pleasure and success (no matter how small)
- “Come back normal”

Implications for clinical practice

Fundamental Division of Labor:

- ◎ **Recovery** is what the person with the mental illness does to manage his or her condition and reclaim his or her life.
- ◎ **Recovery-oriented care** is what health care providers offer in support of the person's own efforts toward recovery and includes enhancing the person's access to opportunities to learn how to manage his or her condition and pursue "a meaningful life in the community."

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
- Case management should be based on the person's ability to identify and set his or her own goals, otherwise it is policing
- Cognitive remediation, like most of rehabilitation, involves a working alliance

- “If you lose your self, then there is no one left to do battle with the illness.” -- Pat Deegan
- “I had to learn how to be human again. I had to relearn how to be a dweller.” -- formerly homeless man in “A Day in the Life”
- “To be able to participate in person-centered care, first you have to believe that you have the right to be a person” -- Ed Knight

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).
- By not perpetuating the culture and practices which contributed to their losing their sense of being a person to begin with.
- By not making decisions for them, doing things to them, or doing things for them without asking (or at least explaining).

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).

“Convalescent maniacs, when, amidst the languors of an inactive life, a stimulus is offered to their natural propensity to motion and exercise, are active, diligent, and methodical ... The first ray of returning talent ought to be seized with great avidity by the governor, and tenderly fostered, with a view of favouring and accelerating the development of mental faculties ... The return of convalescents to their primitive tastes, pursuits, and habits, has always been by me considered as a happy omen of their final complete re-establishment. To discover those promising inclinations, a physician can never be too vigilant; nor to encourage them, too studious of the means of indulgence”.

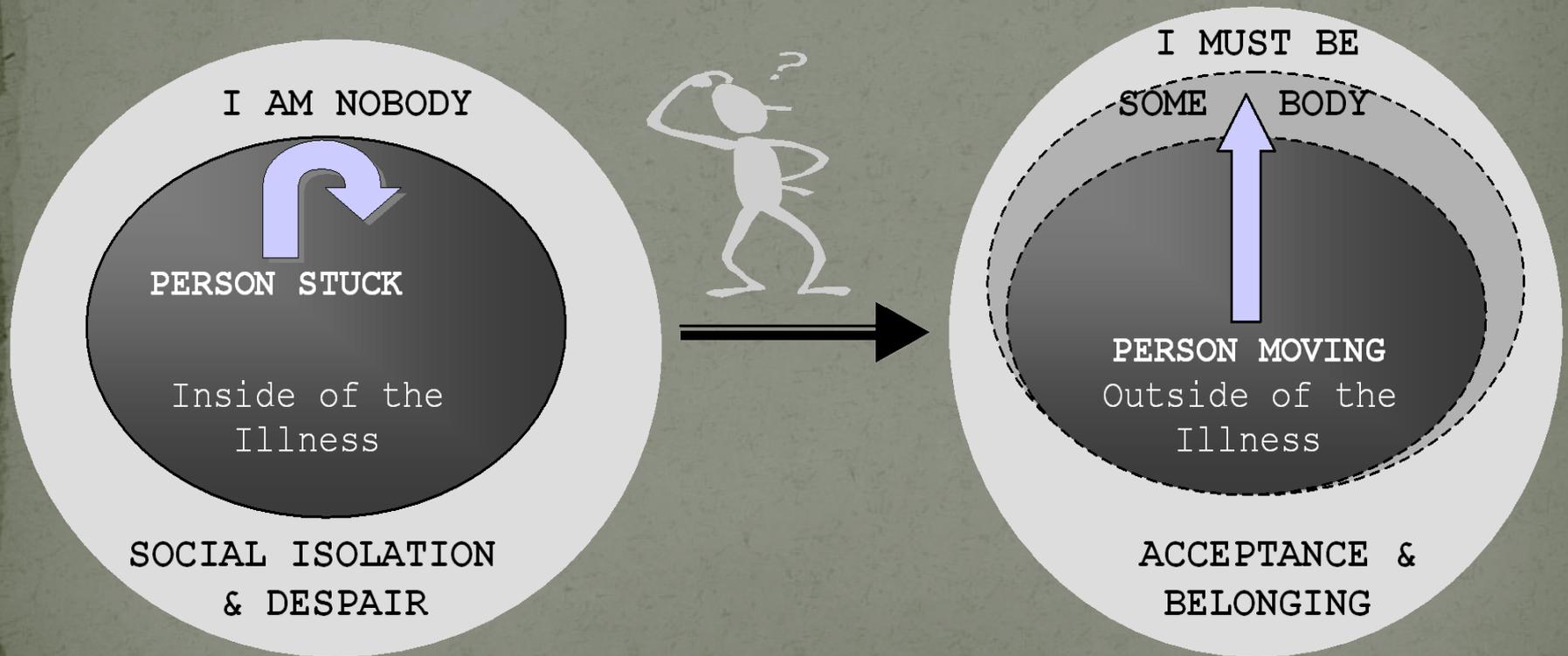


Pinel, 1801

Attention to micro-decisions and acts

“People take for granted that you just do things. A person with mental illness, it’s sometimes hard ... it’s like you’re distracted, you can’t get involved because you’re not sort of all there.”

Establishing a self outside of the illness



Belonging, Meaning & Purpose

- “I could choose to be a nobody, a nothing, and just [say] ‘the hell with it, the hell with everything, I’m not going to deal with anything.’ And there times when I feel like that. And yet, I’m part of the world, I’m a human being. And human beings usually kind of do things together to help each other out ... And I want to be part of that... If you’re not part of the world, it’s pretty miserable, pretty lonely. So I think degree of involvement is important ... involvement in some kind of activity. Hopefully an activity which benefits somebody. [That gives me the sense that] I have something to offer ... that’s all I’m talking about.”

Control and Self-Efficacy

- “I'm in a contest of will with the world, with nature ... and I say to myself: ‘Well, damn it, you just calm down and drink your coffee.’ And I say to myself: ‘You'll just have to wait five minutes.’ So I wait. And then the roommate's still bugging me out [but] then I have the control, the self-esteem, the confidence, and it's manageable. Then I just proudly walk to my room and take space. I mean, it's successful.”

”Basically, if you know recovery...it is more about taking control of your life and what you are going to do....”

“there is this wicked side of me that can stop me. Just like when I’m looking for a job and see a job that would suit me, there is a voice that says, ‘Ah, that’s no job for you’, and stuff like that. And so I have to work a lot with that voice, ‘Oh, shut up, I’m going to apply for that job anyway’.

It’s a struggle going on inside me all the time.”

“My way is to simply see to it that I have something to do, to take a walk, light a cigarette, drink a cup of coffee, eat an apple, watch TV and be on the go. Like, I can't just sit around or lie down and sleep all day, I can't do that. It's just not something I can do. First of all, I can't sleep even when I take a sleeping pill. I've tried but I'm wide awake anyway. I feel well enough now that I want to do something, I want to be active, creative, have some company around me. I want to make something positive of the day, meet people, I want to talk. I'm pretty keen on having company and I don't just lie in bed and sleep all day ... I can't understand how you could waste your days when you only have one life. And so you have to make something of it.”

“Before ... everything was in the long term... Instead, having to hang on, to find strength, I live small moments more intensely. Now we’re here, you and I, and my whole life is all here, only here. It doesn’t matter what else happens... This moment here is more important than anything that might happen tomorrow.

This was definitely decisive for me, this fact of living intensely what I’m doing instead of worrying about the future or other things was a real support, a cornerstone for everything ... a very difficult awareness, a difficult position to take, but living intensely whatever I’m doing, being very concentrated, for me personally ... I did this and no one told me to do it. I did it on my own and it works. For me.”

“So I take it step by step. I have learned to *hurry slowly* and do it in stages and set partial goals when I have discovered that it makes sense ... doing it by partial goals and making it manageable, then you get positive feedback that it’s going okay and then you don’t hit the wall. That’s my strategy, the strategy for success: partial goals and sensible goals and attainable goals, and that’s something I’ve learned to do in order to achieve things. When I have been able to deal with something that’s been a struggle and feel secure, I move on. Step by step, put things behind me.”

“At the bowling alley it doesn’t matter if you’re mentally ill, if you’re a foreigner, an asthmatic, a dyslexic—just as long as you bowl as many strikes as you can you are just like everyone else. So when I’m playing a match I’m worth just as much as anyone else, maybe even more... In a bowling match everyone’s a bowler. It’s the number of strikes that counts, nothing else.”

Useful Questions:

What is worth doing today?*

What does the day demand?***

*Heifetz, R.A. & Linsky, M. (2002). *Leadership on the line*. Boston: Harvard Business School Press.

**Goethe

“You can do it. We can help.”

- Focus on eliciting and enhancing the person’s own sense of control and efficacy, as only the person him or herself can enter into, pursue, and maintain his or her own recovery
- Pay particular attention to the micro-processes and micro-decisions of everyday life. This is because recovery is made up of the same innumerable small acts of living in which we all engage, such as walking a dog, playing with a child, sharing a meal with a friend, listening to music, or washing dishes.
- *It is nothing more but also nothing less.*

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

Providing Community-Based Supports

Purpose/function of psychological and social interventions

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



Image: Clock



Image: Pencil on paper



Image: Woman walking dog



Image: Person in wheelchair at sink

Brief History and Introduction

- Vocational Rehabilitation began during and after World War II.
- Fountain House also started in New York in the 1940s.
- Group homes and residential alternatives arose after the 1954 de-institutionalization initiative.
- By the 1970s, de-institutionalization was being considered a “failed policy” for two main reasons:
 - Funding was never 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 1960s-1970s.

- Based on several lessons

- Many people still needed support.
- Skills did not generalize from a hospital or classroom.
- Learning requires modeling.
- With modeling and support, people could live full lives in the community.



Image: Bicycle



Image: Person lifting car on mechanical jack

In Vivo Support targets Vygotsky's “Zone of Proximal Development”

“... the distance between the actual developmental level as determined by independent problem solving and the level of potential development as determined through problem solving under adult guidance or in collaboration with more capable peers ...”

Zone of Proximal Development (and the Art of Care/Recovery Planning)

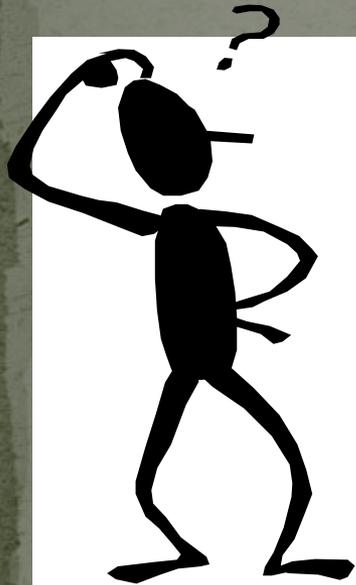


Image: Silhouette of person thinking

**The
Not
Yet
Possible**



Image: Smart Car



Image: Businesswoman
and businessman



Image: House



Image: Newlyweds

The Possible



Role of Activity Analysis

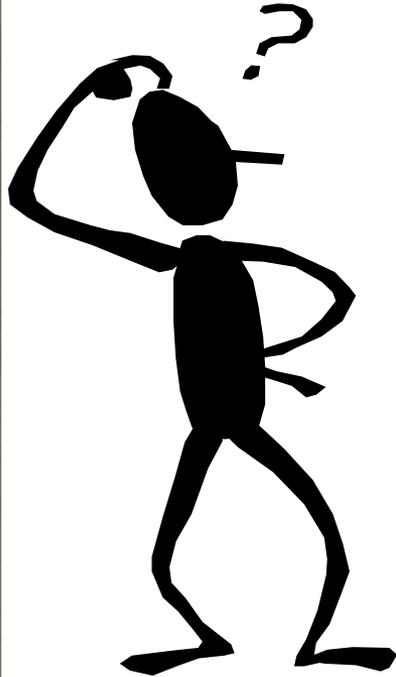
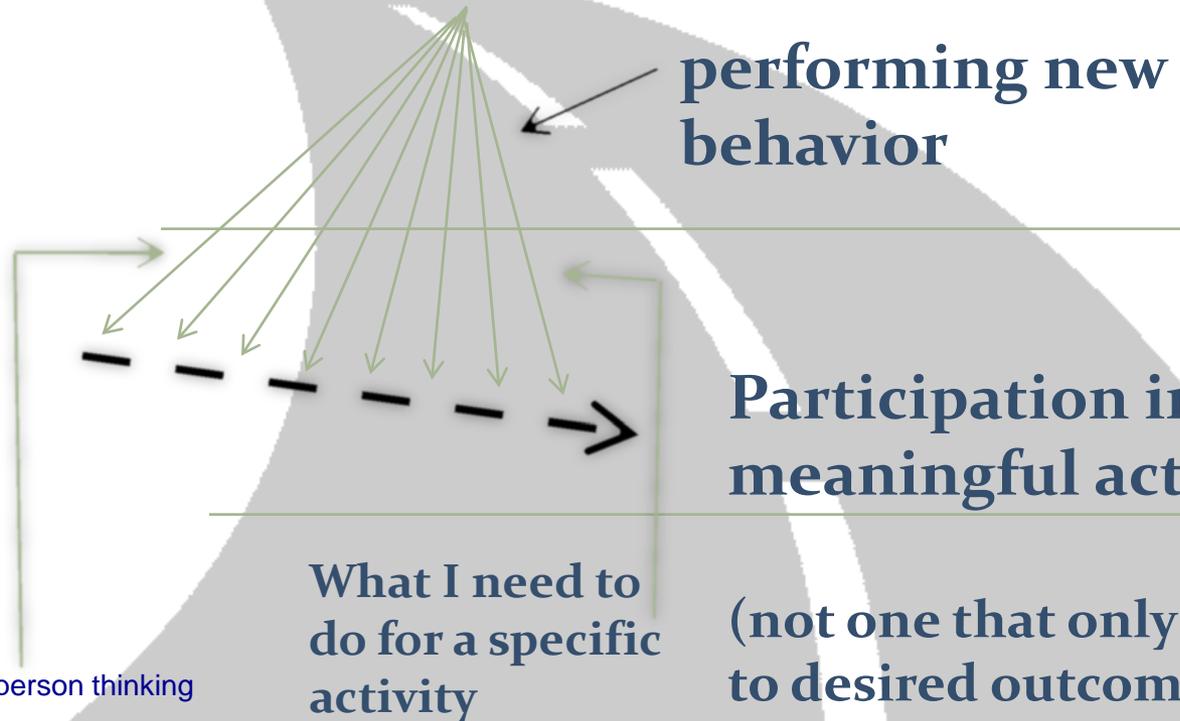


Image: Silhouette of person thinking

**What I can do now
with support
("scaffolding")**



**performing new
behavior**

**Participation in
meaningful activity**

**(not one that only leads
to desired outcome
further down the road!)**

Scaffolding

... is the process by which one person supports another person to acquire new behaviors, skills, and habits through use of the zone of proximal development. The person who facilitates the new learning may be a teacher, mentor, coach, rehab practitioner, or simply a “more capable peer” (from Vygotsky’s original definition)—basically anyone who has already learned the particular action to be modeled for the other person.

Scaffolding involves:

1. non-intrusive instruction and demonstration of tasks within the person’s capacity, and
2. carrying out the remaining parts of the task him or herself.



Image: Scaffolding of building at sunset

Essential Components of Supported Activities

- Enhancing or creating access to opportunities for people to participate in the naturally occurring and personally meaningful activities of their choice.
- Provision of in vivo supports (e.g., personal instruction, scaffolding, emotional support) and environmental accommodations needed for a person to be successful.

This combination has shown promise, as well as results, in improving employment (supported employment), housing (supported housing), education (supported education), and socialization (supported socialization) outcomes, as well as improvements in other important life domains (e.g., supported parenting, supported spirituality).

Lessons Learned Thus Far

- With opportunities and supports, people can live, work, play, learn, and love in naturally occurring community settings.
- Most often, the most important support that can be provided to people with serious mental illnesses is another (trusted) person who can “show them the ropes.”
- Provision of community supports can offer a central role for peer providers who are trained in their provision.
- To be afforded meaningful lives in the community, people must be in the community in order to learn how best to live in it (“integration” is harder than “inclusion”).

Community Integration

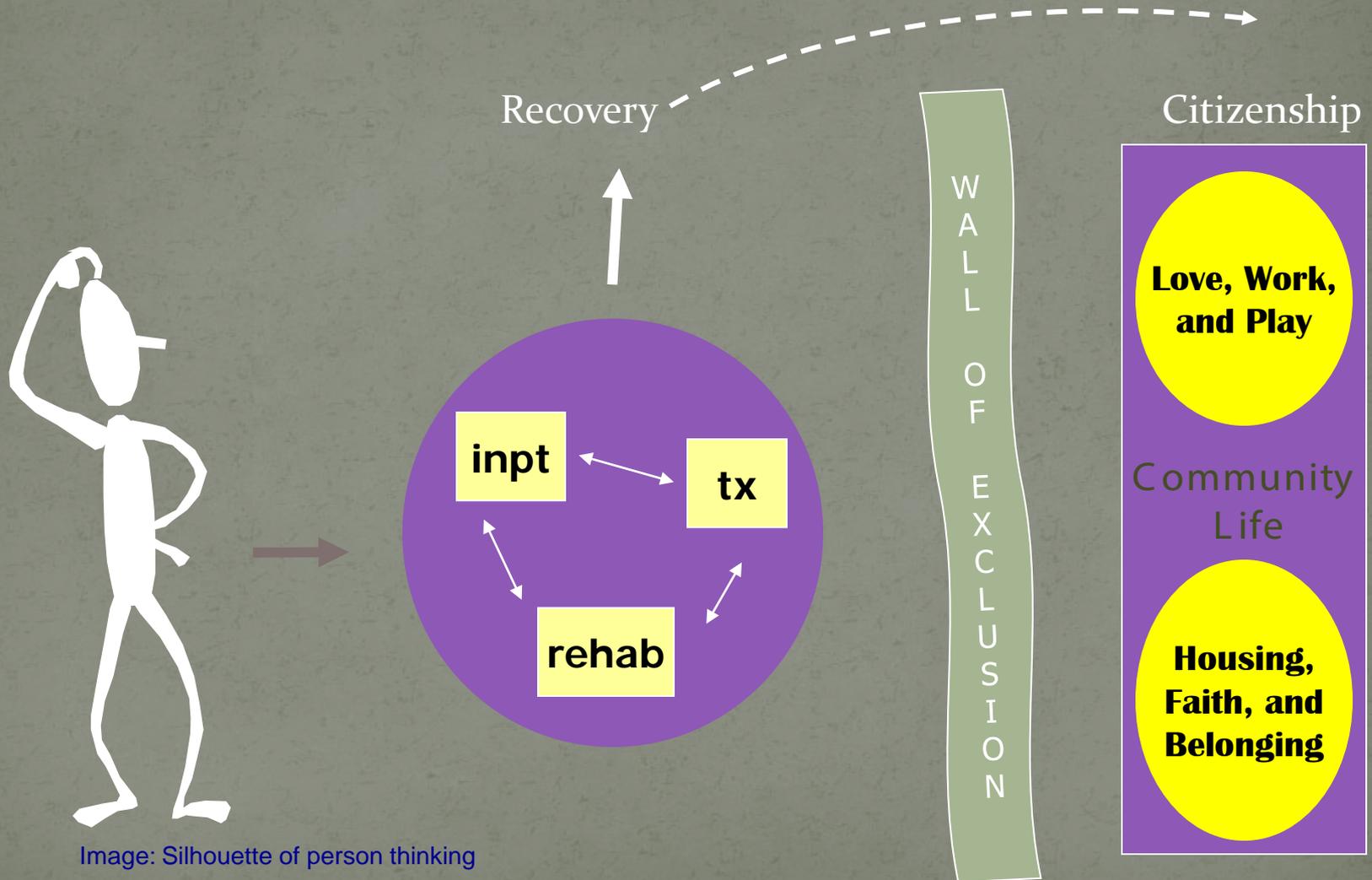


Image: Silhouette of person thinking

Community Inclusion

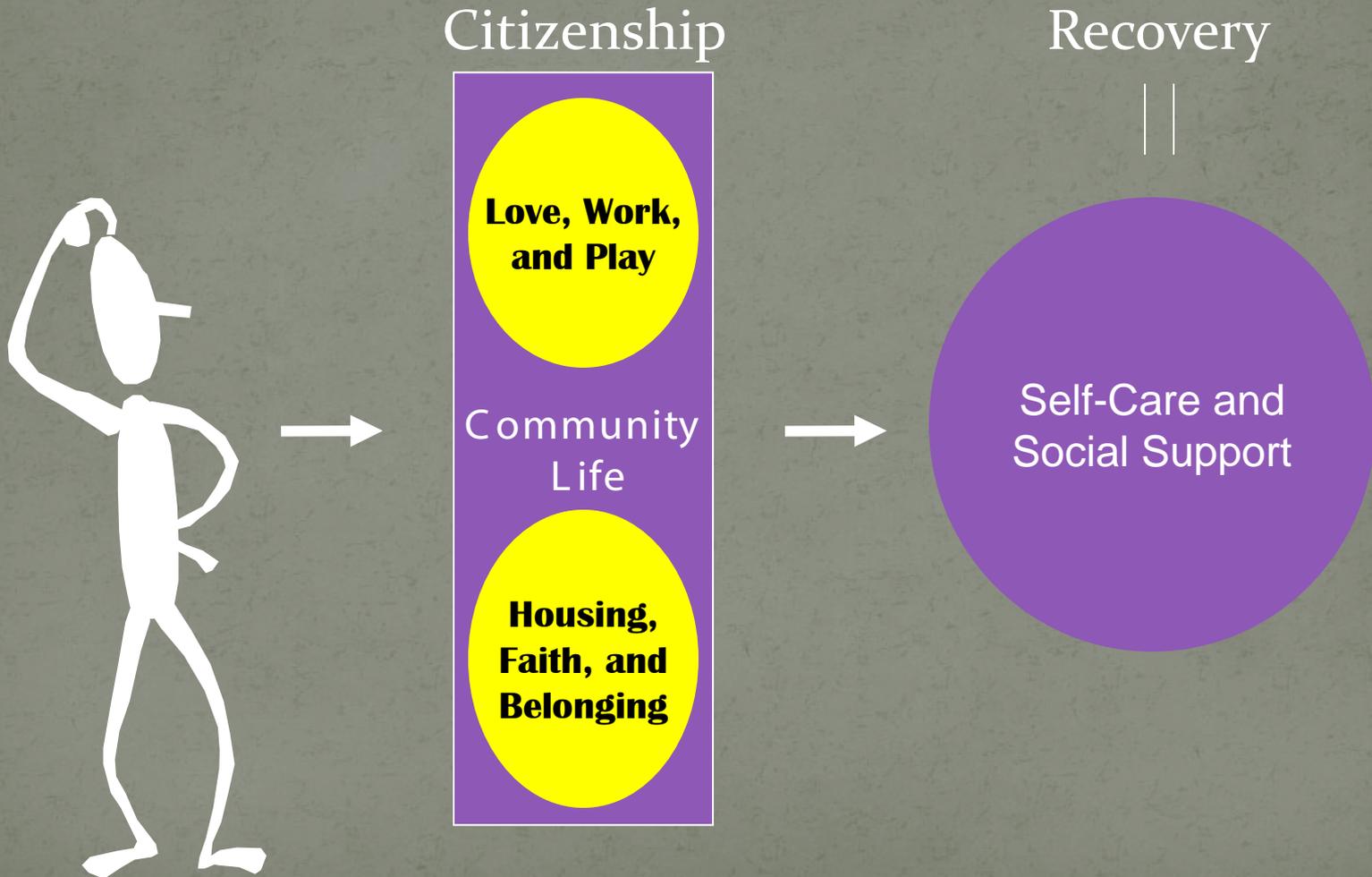


Image: Silhouette of person thinking

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.

Comments?