

# Recovery und Solidarität: Citizenship-Oriented Systems of Care

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# What I hope to cover:

- Distinguishing clinical recovery from personal recovery
- The need for a social justice/disability rights perspective
- Solidarity and giving back in personal recovery
- Implications of solidarity for mental health services and systems
- The structure and functions of a system of care oriented toward recovering citizenship



# Distinguishing clinical recovery from personal recovery

Persistent confusion/skepticism regarding 'recovery' due to competing and contrasting definitions:

*Clinical Recovery* refers to an outcome, to the absence of the signs, symptoms, and impairments associated with the disorder. While it may be manifest in ~68% of persons diagnosed with serious mental illnesses, it may take decades to achieve.

*Personal Recovery* refers to a process involving the reclaiming or recovering of a self-directed and meaningful life despite and in the face of an enduring serious mental illness which may or may not eventually result in clinical recovery.

# *Serious mental illnesses as “psychiatric disabilities”*

“Recovery refers to the lived or real life experience of people as they accept and overcome the challenge of the disability ... they experience themselves as *recovering* a new sense of self and of purpose within and beyond the limits of the disability” - Deegan, 1988 & 1992

Deegan, P. E. (1988). Recovery: the lived experience of rehabilitation. *Psychosocial Rehabilitation Journal*, 11(4), 11-19.

Deegan, P. E. (1992). The Independent Living Movement and people with psychiatric disabilities: taking back control over our own lives. *Psychosocial Rehabilitation Journal*, 15(3), 3-19.



Pat Deegan, Ph.D.



# Need for a social justice and disability rights perspective

- *Clinical recovery* is more a matter of active treatment and rehabilitation, although discrimination and other social factors may impede availability, access, and effectiveness of care
- *Personal recovery* is more a matter of being activated for and engaging in self-management, but then also is influenced by an array of social determinants of health beyond access to care, including stigma and discrimination, unsafe or unstable housing, limited access to education, prolonged unemployment, loss of parenting rights, and lack of inclusion in valued social roles and communities of one's peers (e.g., faith and civic communities).

# Role of the environment in the disability model

- Disability is defined as the result of a person-environment interaction, thus by definition acknowledging the role of social, cultural, and political determinants of mental health and laying the foundation for the use of environmental modifications (e.g., housing in Hawaii)
- The Disability Rights and Independent Living Movements have established justification for funding of long-term supports, thus avoiding the neoliberal critique of society not having responsibility for funding what is described as an individual's responsibility for his or her “personal journey”



# Solidarity and giving back in personal recovery

In addition to rights, Rowe (2014) has defined citizenship in relation to mental health to be comprised of four additional “R’s” along with having a sense of belonging to one’s community as bestowed by others. The 5 R’s are:

- Rights
- Roles
- Responsibilities
- Resources
- Relationships

# “a part of the human race”

“What makes life valuable for those of us with mental illness? ... Exactly what is necessary for other people. We need to feel wanted, accepted, and loved ... We need support from friends and family ... We need to feel a part of the human race, to have friends. We need to give and receive love.” -- Leete, 1993

Leete. E. (1993). The interpersonal environment - A consumer's personal recollection. In Hatfield, A., & Lefley, H. (Eds.), *Surviving mental illness: Stress, coping, and adaptation* (pp. 114-128). New York: Guilford Press.



## “to help each other out”

“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.”

# Reciprocity and “giving back”

“It made me feel like I was being helpful and in situations like that I don’t think so much about my illness. It kind of goes on the back burner because sometimes I just think about my illness and it seems like when I’m helping somebody or somebody says something nice to me ... as soon as people say that, oh, you look good, things like that, it makes me feel better about myself.”

“By helping others you’re not totally worthless. Like it’s a natural, human characteristic that if you’re able to help others than you’re worth something ... It’s essential to life for people to feel necessary... Giving something to someone else makes you feel worth something yourself.”



# Incremental steps

“I didn’t believe in me because when you get mental illness, all of your self-respect disappears ... your self-esteem goes away. And today I see that I have been in the kitchen making food for 60 people. It came by like baby steps you know ... very slowly, very gradually, you start to notice these positive things about yourself, you start to think in a positive way. I am able to do this, now maybe I can do that ...”

“Helping others helps me not think about my problems. I feel like I have a purpose and can help others. *It feels nice to do that when you are usually the one who needs help from others*”

# Regaining value and self-worth

“Working ... 3 to 4 days a week ... really helped to get me back into society. It helped to make me realize, have a sense of self-worth, and also appreciate that there’s a greater good to helping out, even the little chores we do like sweeping the floor, mopping, cleaning the bathrooms. These little things ... made me feel very important.”

“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.”



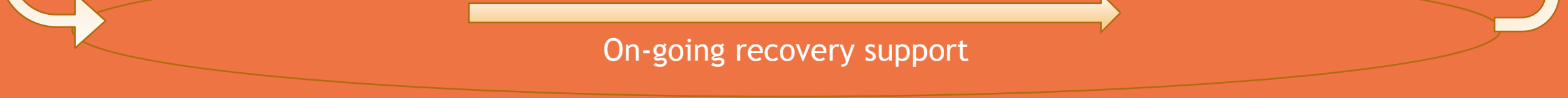
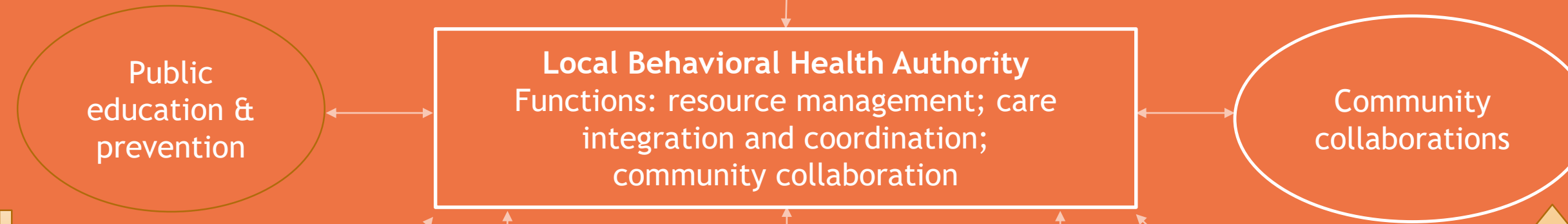
# Implications of solidarity for mental health services and systems

- People with psychiatric disabilities need access to opportunities to contribute to their communities, along with the community-based supports that may be needed for them to be successful.
- In addition to supported housing, employment, and education, this requires access to volunteering, belonging to communities of like-minded equals (faith communities, hiking groups or other athletic activities, pet ownership, civic responsibilities, etc.)
- Systems need to see beyond arrays of evidence-based treatments and rehabilitation programs to fostering pathways for people to travel to connect to their interests, aspirations, values, and peers.

# The structure and functions of a system of care oriented toward recovering citizenship

- Reduction of symptoms, signs, and impairments, while helpful in decreasing suffering, is not enough
- Continuity of care, while important for effectiveness, is not enough
- Provider competencies, while key to obtaining outcomes, are not enough
- Instilling hope, treating people with dignity and respect, and caring genuinely, while necessary and humane, are not enough





**“if you have people saying that you can, you can try little things at a time”**

“When I am on the job, I do my job. I think everybody is capable of doing something. For many years, I did nothing. I was over-medicated and lay on the couch. That is the way I thought my life would always be. Now, the whole thing of mental health is changing. It's really wonderful to see all these changes. Years ago, you didn't have much to look forward to. I thought I would spend the rest of my life in an institution. Now look at what has happened. I had a lot of people who pushed me along the way. I still have issues with self-esteem but if you have people saying that you can, you can try little things at a time.”



**“They help you do things that you can do ...”**

“There has been a lot of progress in the mental health field. I think that the mental health field has changed. I think it is very pro-client, pro-patient. When I deal with people, I find that they are very concerned. They really want to help you... Staff doesn't push you to do things that you aren't able to do. They help you do things that you can do. They help you find goals. I think that the profession has improved a million times.”

# Comments and questions?

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**Thank you!**