We are a Conspiracy of Hope
How do we create hope filled, humanized environments in which people can grow and fulfill their human potential?

Life in Handicaptivity

Treatment Success?

- Reduced costs
- Reduced recidivism
- Increased community tenure

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Me | Psychiatrist
---|---
I feel sedated | You are not psychotic
I’m still hearing distressing voices | You are not shouting at your voices anymore
I can’t think clearly on this medicine | You are not thought disordered
I feel like the meds are controlling me | You are more in control
I’m not myself when I’m on this medicine | You have returned to baseline

### Maintenance Model
- Chronic disease
- Guarded hope for remission
- Meds, Manners and Money
  - Supervised, congregate living
  - Lifetime on benefit checks
  - Day activity in segregated programs
- Lives devoid of meaning and purpose

### Comparison of Vermont and Maine Studies

<table>
<thead>
<tr>
<th>Domain</th>
<th>Vermont (Years)</th>
<th>Maine (Years)</th>
<th>Years difference</th>
<th>Vermont (%)</th>
<th>Maine (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>60-76</td>
<td>13.0</td>
<td>0.0</td>
<td>13.0</td>
<td>50.0</td>
</tr>
<tr>
<td>Independent</td>
<td>60-71</td>
<td>46.4</td>
<td>0.3</td>
<td>46.4</td>
<td>25.6</td>
</tr>
<tr>
<td>Halfway House</td>
<td>60-63</td>
<td>6.2</td>
<td>0.3</td>
<td>6.2</td>
<td>0.3</td>
</tr>
<tr>
<td>Boarding Home</td>
<td>63-71</td>
<td>14.4</td>
<td>3.9</td>
<td>14.4</td>
<td>3.9</td>
</tr>
</tbody>
</table>

### Recovery

Recovery means finding *my* reason to get out of bed in the morning.

I was not a hopeless case. Rather, I was in a treatment system that had no hope. There were no pathways into a better life.
We are not the problem…

...we are part of the solution!

Drowning in Help #1

Drowning in Help #2

Drowning in Help #3

The Moral of the Story

• There may be too many reports on drowning and not enough life preservers
• Help isn’t help if it’s not helpful to the person receiving services. It can be toxic help
• Help is co-created

Health Care is Co-Created

• 2 experts in the room
• Exchange information
• Co-investigators in finding a pathway into a better life
• Shared decision making

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The Other 5,000 Hours

- The principal source of healthcare is self-care
- Self care *is* primary care

Personal Medicine:
It’s what I *do* to get well and stay well

Cascading Effect of Personal Medicine and Psychiatric Meds

Learn strategies to cope with voices = ...

...Less meds = more energy

More energy = able to exercise = ...

...Able to meditate and pray = ...

...Stronger sense of self = ...

Affirmation

Recovery means changing our lives, not our biochemistry

Sylvia

My Personal Medicine

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Recovery: A disruptive innovation

Worcester State Hospital

- Opened 1833
- Samuel Woodward first superintendent
- Moral Treatment
  - Kindness
  - No Physical Restraint
  - Work
  - Exercise/Nutrition
- The goal of treatment was recovery

Follow-Up Study of 1,157 Patients Discharged As Recovered Through 1893

- Remained well and living at time of reply
  - 317 people total
  - 166 males/151 females
- Remained well through life
  - 251 people total
  - 113 males/138 females
- 58% of those discharged remained recovered
  - 568 of 984 remained fully recovered

Interpretation: Evidence Against Recovery

“...there can be no doubt that the public have been hitherto widely misled as to the meaning of the word ‘recovery,’ as used in the hospital reports, and as to the permanency of cures from insanity. Not a small number of patients who were discharged recovered in earlier reports of this hospital have many times since become a burden to the public or private purse by reason of a return to their malady.”

WSH Annual Report XLIX

The Quest for Cure Replaces Recovery

“The majority of the insane are not likely to, and, as a matter of fact, do not recover...In the judgment of the medical profession, further advance in our knowledge of the pathology of the structural changes (of the brain) is best assured in the revelations which the microscope will furnish.”  

Like the sea rose, recovery endured a long winter

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Through the Consumer/Survivor/Ex-patient movement, recovery has re-emerged

An historic window of opportunity

You won’t find the word “recovery” here...

CommonGround: Assistive Technology Helping People Prepare to Participate in Recovery and Shared Decision Making

Pat Deegan PhD & Associates, LLC
A small band of disruptive innovators

Our Vision:
In today’s healthcare environment, there is no time for waiting in waiting rooms
• Prepare
• Participate
• Shared Decision Making
• Engage in self-care
• Recover

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Before the appointment

From home

From the field

From the clinic

Prepare My Health Report

During the meeting with my team

What we have learned:

- 21,017 users
- 58+ sites in 8 states
- 68% shared decisions for 107,259 Health Reports across all clinics

Shared decision making CAN happen in real world settings when supported by CommonGround technology

CommonGround Recognition

A new role for peer supporters

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Personal Medicine

It’s what I do to be well

Power Statements

It’s how I advocate for treatment to support my recovery

Power Statement

The most important thing in my life is working at Pizza Hut. I want my medication to help me focus on my work, not my voices, so I can pay attention at my job. I want you to work with me to stay out of the hospital so I can continue to work at Pizza Hut.

Recovery Discovery

When to talk with the psychiatrist or nurse about reducing mental health medicine

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Safeguard Our Conspiracy of Hope

- Engage with people, not illnesses
- We are not the problem, we are part of the solution
- We can lead a meaningful life even though some symptoms persist
- Self-care is primary care
- Help is co-created
- Cars get fixed. We heal and grow
- Medication should support recovery, not disable us
- Discover your Personal Medicine

Recovery: A pathway into the life I want for myself

Our Conspiracy of Hope