WELCOME

Professor Larry Davidson, Yale University, School of Medicine

PUBLIC LECTURE
The contribution to mental health reform by people who have experienced mental health challenges

Larry Davidson, Ph.D.
Professor of Psychiatry, Yale School of Medicine
Project Director, Recovery to Practice
SAMHSA, US Department of Health and Human Services
How to reform mental health care to promote recovery?

Some things we can do:

• Decrease stigma, discrimination, and other barriers to access to care

• Facilitate early identification and ensure timely access to early intervention

• Utilize practices that are effective (i.e., that are evidence-based)

• ?
But is this enough to ensure reform or recovery?
We know that...

• Only about 1/3 of individuals in need of specialty mental health care for a serious mental illness receive that care

• Even fewer people currently receive effective care in a timely fashion (~17%)

• Current interventions are limited in their efficacy (e.g., to 70% of persons with psychosis, to positive symptoms only, etc.)

• Less than 20%, and as low as 5%, of those being prescribed medications are receiving the most appropriate and effective care available (i.e., care that is evidence-based)
We also know that ...

• About 80% of people will be rehospitalised within 5 years following a first episode of hospitalization.

• Cognitive remediation has small-to-moderate effects on neuropsychological performance that does not generalize to everyday life.

• Supported employment is received by less than 1% of the population and tends to lead to part-time jobs, with job tenure averaging < 6 months, and monthly earnings averaging only $122/month or $1,464/year.

• ACT increases housing stability and moderately improves symptoms and quality of life, but also is received by very few people—as are most “evidence-based practices” (less than 5% of persons with SMI).
If this were all we knew, there would be ample cause for pessimism and concern...

However, we also know that...
What we know about recovery

- Domains of functioning are only loosely linked
- There is a broad heterogeneity in outcome
- 45-65% of people with psychosis experience significant improvements over time, many recovering fully
- The vast majority of persons who would have been institutionalized prior to 1954 are now living in the community (from 500,000 to 50,000 in the U.S.) many of them taking care of themselves after experiencing significant improvements 10-15 years into the course of illness
An intriguing discrepancy

- Few people (~5%) benefit from the few effective interventions we have, and the effects of these treatments are only small to moderate.

- Yet over half of these people will experience partial to full recovery over time, with only about 15-25% experiencing a deteriorating condition.

How are we to understand this?
Service users suggest that

• While we can’t (yet) cure the illness...

• Many people (most) figure out how to live a decent life with the illness

• And with effective services and supports, many can lead even better lives than they would on their own.
What else there is for us to do?

We need to:

• Rethink relationship of care to recovery

• Rethink the role of practitioner

• Shift focus from what we can’t change to what we can

• Learn from people in recovery.
Two common reactions

• Recovery is not possible for my patients. Talking about “recovery” with them just builds up false hopes and is cruel

• There is nothing new about recovery. We already practice in a recovery-oriented way. It’s just a new name for old values
Let’s get concrete.

Recovery-oriented care is different.
The story of “Steve”

In his frequent efforts to promote the transformation agenda in Connecticut, Commissioner of Mental Health and Addiction Services, Tom Kirk, Ph.D., tells the story of a 27 year-old man named Steve who he met during a visit to a supported housing program.

When he asked the staff how Steve was doing in his recovery Commissioner Kirk reports that they responded favorably about how well Steve was doing in the program; following the rules, taking his medication as prescribed, and having his symptoms relatively under control.

When asked if this was the kind of life they hoped for this young man for the foreseeable future the staff seemed puzzled, confident that they were doing their best. His condition after all, was stable and he had not been admitted to the hospital for several years. Commissioner Kirk, however, was not satisfied. He asked the staff to go one step further and consider whether or not this would be the kind of life that would make them content were they in Steve’s place.

Once it was phrased this way, the staff began to think that more could be done for, and more could be expected from, this clever college graduate who was engaging, loved cars and racing, and had aspirations of becoming a mechanic. But how could they help him with that? They had little idea as to what they could do beyond treating his schizophrenia and encouraging him to participate in program activities as a way of luring him away from his television set. Becoming a mechanic seemed a long way off, if it was to be possible at all.
The Crux of the Problem

Well, this is a very impressive resume, young man. I think you're going to make a fine patient.”
What lessons can we learn from Steve’s story?

• People with mental illnesses may want the same things out of life as other people do

• People are not their diagnoses, are not subsumed entirely by the illness, and continue to exist alongside of the illness

• Mental health care has addressed illness and its symptoms more so than the person and his or her everyday life
Your challenge

• How to stop accepting long-term disability, and begin to promote long-term functioning and meaningful (self-determined) community inclusion?

• What kind of “revolution” in care are we talking about?

• How to assure people with serious mental illnesses that they have retained the right to be a person and to be a full citizen of their community?

• How to support them in doing so, even when the illness does not go away?
Your challenge

• “Revolutions begin when people who are defined as problems achieve the power to redefine the problem” John McKnight

• People who are now seen as ‘burdens’ on a system (and a state) come to be seen as the system’s greatest assets

• ‘Patients’ become reform leaders
Otherwise said:

• You can’t transform your system alone, any more than you can cure mental illness (or addiction) alone

• There is no way to create a “consumer-driven” system without consumers (i.e. people in recovery) driving it.

• Like recovery-oriented practice, it requires a collaborative approach based on what people in recovery value, need, and can make use of in living their lives as best as they can
People in recovery

• ...are a primary source for identifying strengths and charting a course forward

• ...have the most at stake; the most to gain and the most to lose in the process

• ...can be the most effective antidote to stigma and discrimination (putting a positive face on recovery/mental illness)

• ...have a strong desire to “give back” and have a lot to offer (energy, ideas, support).
A beginning blueprint for where you might go from here

• Conduct a strengths-based assessment of what is working well in your current system and what areas people in recovery, their loved ones, and other stakeholders would like to see improved first.

• Articulate a shared vision of where you are heading. What implications does the recovery paradigm have specific to Australia? What will it take to afford people “a full life in the community” in your state or country?

• People can no longer be kept in institutions for prolonged periods against their will. But it is up to each person him or herself (with his or her loved ones) to decide what kind of life he or she wishes to lead in the community. Mental health services support that
• Identify ways in which existing strengths can be used to build on in taking the next few steps toward this shared vision

• Develop an action plan at each level of the system, including local communities, which builds on these strengths, including, importantly, the contributions of the recovery community

• Include the recovery community (and family and other allies) in all aspects of transformation, including design, implementation, evaluation, and analysis
But how could ‘our patients’ know what needs to change?

• When it comes to diagnosing and treating illnesses, or assessing and remediating deficits, we have the expertise

• When it comes to living a meaningful life in the community, each person has the right to determine what kind of life he or she wants to lead—and the “expertise” to know what they need in order to do so

• When little is expected, little is delivered. When much is expected, people have the tendency to rise to the occasion. When asked (and if they believe you will listen), people have tremendous amounts to offer
Where we have come from
(not so long ago)

This was what we thought mental illness looked like
A new vision

• People in recovery are actively and meaningfully involved throughout all aspects of service provision and comprise a significant proportion of boards of directors, advisory boards, or other steering committees and work groups

• People in recovery are routinely invited to share their stories with service recipients and/or to provide training to staff

• People in recovery have maximum opportunity for informed choice and decision-making in their own care

• Staff encourage individuals to exercise their responsibility and make meaningful contributions to their own recovery and to the community as a whole
• Measures of satisfaction with services and supports are collected routinely and used in a timely fashion to guide strategic planning and quality improvement initiatives

• Administration prohibits the use of coercive practices and holds staff accountable for affording people maximum choice and decision-making in their own care

• Active recruitment of culturally diverse people in recovery for existing staff positions is coupled with ongoing support for the development of a range of peer-operated services that function independent of, but in collaboration with, professional agencies
• Self-disclosure by employed persons in recovery is respected as a personal decision. Rather than being prohibited by agency policy or practice, it is encouraged as a way to dispel stigma.

• Process and outcomes evaluations are continuous processes and are not limited to the absence of symptoms or maintenance of clinical stability.

• Statistics on outcomes and satisfaction are made public so that individuals can make informed decisions.
• Information is provided in a variety of formats to enable people in recovery and their loved ones to make informed choices and to provide meaningful input

• Each person receiving care is provided with an initial orientation to agency practices regarding their rights, complaint procedures, advance directives, access to their records, rehabilitation and community resources, and spiritual/chaplaincy services

• People seek information about their concerns, review their options, ask questions about issues relevant to them, and are offered decisional aids and other tools to enable them to make informed choices about their care
Action plans need to include:

• Building a system-wide, shared understanding of recovery and recovery-oriented practice, along with developing the internal capacity of the system to carry out recovery-oriented training

• Aligning system functions such as:
  • Service design and reimbursement mechanisms
  • Outcomes monitoring
  • Provider performance measures
  • Human resources protocols
  • Credentialing and licensing regulations etc.

  with recovery orientation and the increasing role of peers
System Transformation Inventory

A. How people with behavioral health conditions are viewed and treated by staff.

B. How people with behavioral health conditions are included in the design, delivery, and evaluation of care.

C. How care is planned, delivered, and improved on a continuous basis.

D. How transformation is led and managed.
## Transformation inventory

### A. How people with behavioral health conditions are viewed and treated by staff

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<tr>
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<th>Pre-Transformation</th>
<th>Degree to which ...</th>
<th>Post-Transformation</th>
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<tr>
<td>1</td>
<td>People with behavioral health conditions are viewed as “chronic mental patients,” “addicts,” or “mentally ill.” They may commonly be referred to as “schizophrenic,” “bipolar,” or “borderline.” The diagnosis comes before the person and is thought to be permanent and to take over the person. Recovery is considered to be extremely rare, if possible at all.</td>
<td>People with behavioral health conditions are viewed and treated as people</td>
<td>Research on outcomes in mental illnesses and addictions has been disseminated to staff. Staff understand that these conditions do not define people and recovery is not only possible, but is more common than long-term impairment. Staff use person-first language to indicate that the person is more important than the condition.</td>
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<td>2</td>
<td>Staff are largely unaware of the mental health consumer movement and/or the new recovery advocacy movement in addiction. They view issues of civil rights and discrimination as irrelevant to behavioral health conditions, services, and systems. People being served and their families are treated as “less than” by staff, are viewed as being one down in relation to staff expertise and power, and are expected to “comply” with staff instructions.</td>
<td>Civil rights are respected</td>
<td>Staff have been educated about the mental health consumer and new addiction recovery advocacy movements. They are aware of how persons with these conditions were treated as “second class” or less than human in the past and attend to the civil rights dimension of recovery/resiliency in their work both inside and outside of the behavioral health system. People being served and their families are held in high regard and treated with dignity and respect. They are viewed as active agents in their own recovery and as partners in collaborative relationships with staff.</td>
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<td>3</td>
<td>Staff are not aware of success or recovery stories in their local community. They do not know people who are open about their recovery or about being in recovery. Staff have low expectations for the people they serve. They assume that these persons’ lives will forever be limited or diminished by the presence of a mental illness and/or addiction, and cannot imagine the person thriving or flourishing. The basic message conveyed by staff is: “Mental illnesses and addictions are life-long, chronic conditions from which you will never recover.”</td>
<td>Staff know about and expect resilience and recovery</td>
<td>Success stories of local people who have been resilient and entered into recovery are made public and are commonplace. Staff invite such people back to share their recovery narratives with current service users to instill hope and encouragement. Staff view each person they serve in their unique individual who is contending with a mental illness and/or addiction, but who also has hopes, dreams, and aspirations and is worthy of being loved and capable of loving others. The basic message conveyed by staff is: “People can recover. You can overcome or live with this condition and have a full and meaningful life.”</td>
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In the end...

Transformation is not about doing new things on top of what you are doing already.

It is about doing what already works well more and doing other things (that don’t work well) differently, with a significant emphasis on redistributing the labor involved.

People with mental illnesses can be “in recovery”

Our job is to support them in their efforts.
HAVE YOUR SAY...

The Mental Health Commission of NSW is calling for registrations to contribute to the draft Strategic Plan for Mental Health in NSW

For more information and to register go to: [www.nswmentalhealthcommission.com.au](http://www.nswmentalhealthcommission.com.au)

or call 1300 884 563.
Link to video of Melbourne event:
http://www.youtube.com/watch?v=38ImiRBo_MM&feature=youtu.be