Recovery, Empowerment and Self Determination:
A Vision for the future of Public Mental Health Systems

Virginia Association of Reimbursement Officers

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September 20, 2006
Chronic and Serious Mental Illness

- **Psychosis:**
  - “break or disconnection from reality”

- **Schizophrenia** (literally “split mind” – but not split personality)
  - Delusions
  - Hallucinations
  - Disorganized speech
  - Grossly disorganized or catatonic behavior
  - Negative symptoms
  - Types
    - Paranoid
    - Disorganized
    - Catatonic
What is Recovery?

- Patricia Deegan, Ph.D.
What is Recovery?

- Current Notion dates back to mid-1980’s
  - Harding’s (1987) Vermont Longitudinal Study that showed the course of severe mental illness was NOT inevitable deterioration.
  - Several first person accounts of “recovery”
    - Deegan (1988)
    - Fisher (1992)
    - Copeland (1994)
Harding et al. Study

- Sample size: 269
- Average length of follow-up: 32 years
- Rates of significant improvement or recovery for schizophrenia:
  
  ✓ 62-68%  


(From Deegan’ Lessons in Recovery and Resilience)
Harding et al. 1987 Study

- Recovery defined as four criteria:
  - Having a social life similar to others in the wider community
  - Holding a paying job or volunteering
  - Being symptom free
  - Being off of psychiatric medications
- 62% of people diagnosed with schizophrenia met 3 of the 4 criteria

(From Deegan’ Lessons in Recovery and Resilience)
Tsuang et al. Study

- Sample size: 186
- Average length of follow-up: 35 years
- Rates of significant improvement or recovery for schizophrenia:
  ✓ 46%


(From Deegan’ Lessons in Recovery and Resilience)
Ogawa et al. Study

- Sample size: 140
- Average length of follow-up: 22.5 years
- Rates of significant improvement or recovery for schizophrenia:
  ✔ 57%


(From Deegan’ Lessons in Recovery and Resilience)
DeSisto et al. 1995

- Sample size: 269
- Average length of follow-up: 35 years
- Rates of significant improvement or recovery for schizophrenia:
  ✓ 49%


(From Deegan’ Lessons in Recovery and Resilience)
Longitudinal Studies: Recovery Rates

(From Deegan’ Lessons in Recovery and Resilience)
Assumptions about Recovery

- Recovery is highly individualized
- Recovery can occur with recurrent symptoms
- Recovery from Stigma if mental illness is sometimes more difficult than recovering from illness itself

Adapted from Anthony, Deegan and others
Assumptions about Recovery

- Recovery is not the same as cure
- Recovery is having more to life than illness
- Recovery is a process, not a destination
- Recovery is both done and defined by the person

Adapted from Anthony, Deegan and others
Recovery

- Rehabilitation is what professionals do
- Recovery is what consumers experience
  - The person’s own experience is in the center of recovery
“Perhaps the process [recovery] is elusive precisely because it is so fundamental”

- Deegan
DSM-IV-TR (2000)

“… an accurate summary of the long-term outcome of Schizophrenia is not possible. Complete remission (i.e., a return to full premorbid functioning) is probably not common in this disorder. Of those who remain ill, some appear to have a relatively stable course, whereas others show a progressive worsening associated with severe disability.”
DSM-III (1980)

- “The most common course [of schizophrenia] is one of acute exacerbations with increasing residual impairment between episodes.”
“Dramatic improvement in a patient with a diagnosis of schizophrenia was regarded by many clinicians as evidence of original misdiagnosis”

- Rund, BR; Fully Recovered Schizophrenics: a retrospective study of some premorbid and treatment factors. Psychiatry 1990; 53:127-139
“Relatively little attention has been paid to the role of neuro-degenerative processes [in Schizophrenia] despite the clinical course of the illness and the fact that most patients experience varying degrees of behavioral and cognitive deterioration.”

– J. Lieberman, Biological Psychiatry (1999)
“Studies in Europe, the United States, Japan that followed up persons who experienced disabling forms of schizophrenia during adulthood found, 20 to 40 years later, a remarkable 50 to 66 percent functioning actively in their communities with few symptoms, a reasonably good subjective quality of life, and only limited dependence on professional caregivers.” (R. Liberman)

― These findings have spurred interest in psychiatric rehabilitation as a way to facilitate social and symptomatic recovery of seriously mentally ill persons.‖

(R. Liberman)
Remission in Schizophrenia: Proposed Criteria and Rational for consensus

- American Journal of Psychiatry, March 2005
- Nancy C. Andreasen, M.D., Ph.D., et al
- Remission in Schizophrenia Working Group
- “To Develop a Consensus Definition of Remission as applied to Schizophrenia”
Remission in Schizophrenia: Proposed Criteria and Rational for consensus

“The need for such a definition is timely because…evidence that traditional predictions of generally poor outcome may have been overstated.”

Nancy C. Andreasen, M.D., Ph.D., et al
Am J Psychiatry 2005; 162:441-449
Myths about Schizophrenia

- Inevitable downhill course of illness
- Rehabilitation useful only after stabilization
- Medications needed forever
- People with MI can only work at low-level jobs
Achieving the Promise:
Transforming Mental Health Care in America
President’s New Freedom Commission on Mental Health

Achieving the Goal: Recommendation 2.2

Involve consumers and families fully in orienting the mental health system toward recovery

Vision Statement:

“We envision a future when everyone with a mental illness will recover…”
The term “Recovery” has led to Confusion/Conflict

- **Consumers**
  - Who are expected to recover

- **Professionals and Policy Makers**
  - Who are expected to help them
The Top Ten Concerns About Recovery Encountered in Mental Health System Transformation

- Recovery is old news. “What is all the hype? We’ve been doing recovery for decades”
- Recovery-oriented care adds to the burden of mental health professionals who already are stretched thin by demands that exceed their resources.
- Recovery means that the person is cured. (When clearly the person is still very disabled.)

Davidson et al.; Psychiatric Services May 2006
The Top Ten Concerns
(Continued)

- Recovery happens for very few people with serious mental illness
- Recovery in mental illness is an irresponsible fad
- Recovery happens after, and as a result of, active treatment and the cultivation of insight
- Recovery can be implemented only through the introduction of new services

Davidson et al.; Psychiatric Services May 2006
The Top Ten Concerns (Continued)

- Recovery-oriented services are neither reimbursable nor evidence based.
- Recovery approaches devalue the role of professional intervention.
- Recovery increases providers exposure to risk and liability.

- Davidson et al.; Psychiatric Services May 2006
The Top Ten Concerns (Continued)

“Once it is firmly established, the recovery vision will allow us to see, albeit in retrospect, that the costs incurred by not taking such risks – the costs of chronicity, institutionalization, and homelessness – far outweigh the cost of doing so.”

Davidson et al.; Psychiatric Services May 2006
What is Recovery?
A Conceptual Model
Jacobson and Greenley; Psych Services; April 2001

- **Internal Conditions**
  - Attitudes, experiences and processes of change of individuals who are recovering
    - Hope
    - Healing
    - Empowerment
    - Connection

- **External Conditions**
  - Circumstances, events, policies and practices that may facilitate recovery
    - Human Rights
    - A positive culture of healing
    - Recovery-oriented services
Recovery

Internal Conditions

Connection  Healing  Empowerment  Hope

Jacobson: N, A Conceptual Model of Recovery
Connection: rejoining the social world or “getting a life”

Recovery is a profoundly social process

For many, this means helping others who are also living with mental illness

– Becoming provider
– Peer support
– Advocate
– Telling personal story
Healing

– Recovery is NOT synonymous with ‘cure’

– Recovery concept is not necessarily a return to “normal”

– Two components of Healing in Recovery:
  » Defining the self apart from illness
  » Control
Process of Recovery

The Person

The Illness

The Person

The Illness
I’ve finally decided,
With some inner will, -
That I’m too busy,
To be mentally ill,
I take my meds,
And try to think,
Sitting and talking,
With the shrink,
I am so busy,
I don’t have time,
To think about it,
All the time.
I’m so busy,
Be assured,
I won’t even noticed,
If I am cured.

- Dylan Abraham
Empowerment: a corrective for the lack of control and dependency that many consumers develop after long-term interactions with the mental health system

3 Components

- Autonomy
  » Knowledge
  » Self-confidence
  » Availability of meaningful choices

- Courage
  » Willingness to take risks
  » To speak in one’s own voice
  » To step out of safe routines

- Responsibility
Traditional Approach Swaddles Patients with Services

Client
Case Manager

Vocational
Specialized Housing

Culturally Specific Services

Psychotherapy

AODA

Crisis Services

Inpatient
Recovery Oriented System Supports But
Does Not Surround Consumer

Trainor, Pomeroy and Pape 1993
Canadian Mental Health Association
Hope: the individual’s belief that recovery is possible

Attitudinal components of Hope are:
- Recognizing, accepting that there is a problem
- Committing to change
- Focusing on strengths rather than on weakness or possibility of failure
- Looking forward rather than ruminating on past
- Celebrating small victories
- Reordering priorities
- Cultivating optimism

(Jacobson and Greeley)
Models of Recovery

External Conditions

- Human Rights
- Positive culture Of healing
- Recovery Oriented Services

Jacobson: N, A Conceptual Model of Recovery
External Conditions of Recovery

- **Human Rights**
  - Reducing/eliminating stigma
  - Protecting rights of persons in service system
  - Providing equal opportunities (education, housing, employment)

- **A Positive Culture of Healing**
  - Tolerance, listening, empathy, compassion, respect, safety, trust

- **Recovery Oriented Services**
  - Attitude of the professionals who provide them
  - Partnership, collaboration
You and I

By Laurie Curtis

Adapted from a poem also entitled You and I by Elaine Popovic

I am a resident You reside. I am placed. You move in.

I am learning daily living skills. You hate housework. You use a cleaning service, a laundry service and have take-out pizza for dinner.

I get monitored for tooth-brushing. You never floss.

I have to be engaged in a meaningful activity everyday. You take mental health days, holidays and go on vacation.
You and I

By Laurie Curtis

Adapted from a poem also entitled You and I by Elaine Popovicti

I am aggressive. You are assertive. I am aggressive. You are angry.

I am depressed. You are sad. I am depressed. You grieve. I am depressed. You feel stressed and overwhelmed.

I am manic. You are excited. I am manic. You feel passionate and energized. I am manic. You charge to the limit on your credit card.

I am non-compliant. You don’t like being told what to do.

I am treatment resistant because I stop taking medication when I feel better. You never complete a 10 day course of antibiotics.

I am in denial. You don’t agree with how others define your experience.

I am manipulative. You act strategically to get your needs met.
You and I

By Laurie Curtis

Adapted from a poem also entitled You and I by Elaine Popovicti

My case manager, therapist, nurse, doctor, rehabilitation counselor, residential counselor and vocational counselor all set goals for me for next year. You haven’t decided what you want out of life.

I am a consumer, a patient, a client, a survivor, a schizophrenic, a bipolar, a borderline. You are a whole person — complete with your gifts. strengths, weaknesses and challenges in living.

Someday I will be discharged...maybe. You will move onward and upward, perhaps even out of the mental health system. You see, I have problems called chronic; people around me have given up hope. You are in a recovery process and get support to take it one day at a time.
The Disease Centered Model

- **Professional Role**
  - Hierarchical
  - Paternal
  - In-charge
  - Holds the important knowledge
  - Responsible for treatment
  - Disease is focus

- **Patient’s Role**
  - Subservient
  - Obedient
  - Passive
  - Recipient of knowledge
  - Responsible for following treatment
  - Host of the disease
Recovery: Person Centered Model

- **Person’s Role**
  - Personal power
  - Personal knowledge
  - Personal responsibility
  - Person in context of life is the focus
  - Person is self-determining

- **Professional Role**
  - Power sharing
  - Exchange information
  - Shared decision-making
  - Co-investigator
  - Professional is expert consultant on journey
Practical Examples of the Recovery Vision:

- Revision of FRP process
- Seclusion and Restraint reduction
- Policy changes on Pass/leave
- LOS reduction
- TOVA vs Mandt training
TOVA vs Mandt training/interventions

“Violence is the language of the unheard”

-- Martin Luther King, Jr.
"Nearly all men can stand adversity, but if you want to test a man’s character, give him power."

-- Abraham Lincoln
Practical Examples of the Recovery Vision:

- Crisis Stabilization and other community alternative capacity enhancements vs increasing “traditional” inpatient beds
- Crisis Intervention Teams (CIT)
- Mental Health Courts
- Increased involvement of consumers as providers of care
System Transformation Initiative

Over the next biennium the System Transformation Initiative will:

– Provide total community investment of $194.61 million

– Rebuild four state facilities, creating smaller, more efficient state-of-art psychiatric hospitals and training centers for people with mental retardation:

  » Eastern State Hospital (ESH) – Replace facility ($ 59.72 million)

  » Western State Hospital (WSH) – Planning funds ($ 2.5 million)

  » Central Virginia Training Center (CVTC) – Planning funds ($ 2.5 million)

  » Southeastern Virginia Training Center (SEVTC) – Planning funds ($ 2.5 million)
State Mental Health Agency Controlled Expenditures for State Psychiatric Hospital Inpatient and Community-Based Services as a Percent of Total Expenditures: FY'81 to FY'02

- **State Hospital Inpatient**
  - FY'81: 63%
  - FY'83: 61%
  - FY'85: 60%
  - FY'87: 59%
  - FY'90: 54%
  - FY'93: 49%
  - FY'97: 48%
  - FY'01: 58%
  - FY'02: 66% (67%

- **Community Mental Health**
  - FY'81: 33%
  - FY'83: 35%
  - FY'85: 36%
  - FY'87: 38%
  - FY'90: 43%
  - FY'93: 48%
  - FY'97: 39%
  - FY'01: 32%
  - FY'02: 30%
FY’02 Per Capita SMHA-Controlled
Expenditures for Mental Health

[Bar chart showing per capita expenditures for mental health across different states, with categories for SMHA Office & Support, Community Based Programs, and State Psychiatric Hospital Inpatient.]
Consumer identification of what helped in their own recovery

- Generally health professionals not helpful
- But almost all participants able to identify at least one health professional who was very helpful
- More like the relationship one has with a friend
Factors Identified By Consumers As Most Important To Their Recovery

- Determination
- Illness Management
- Self-Help
- Having Friends Who Accepted Them
- The Negative Effects Of Medication
- The Negative Effects Of Health Professionals
- Accepting The Illness
- Crisis Response As Part Of The Process
- Struggling With Their Ability To Recover

Tooth, Kalyansundaram and Glover
Recovery from Schizophrenia: A consumer perspective
1998
Meds Alone Couldn’t Bring Robert Back  February 6, 2006

Experts like to debate the effectiveness of new drugs, but they overlook a key element of recovery.

What had made the difference?

Some pointed to new medications, some to old; some said they had found God; some attributed their transformation to a particular program, but no matter what else they named, they all—every last one—said that a key element was a relationship with a human being. Most of the time, this human being was a professional—a social worker, a nurse, a doctor. Sometimes it was a clergyman or family member.

In every instance, though, it was the presence in their lives of an individual who said, in effect, "I believe in your ability to recover, and I am going to stay with you until you do" that brought them back. So it was with my brother, who, through his daily collaboration with Alan and the dedication of Dr. Pam (who refused to go along with the staff consensus that Robert would never live on his own) has not had a single recurrence for more than six years, the longest stretch in his adult life.

Power to Heal: Due to the dedication of Dr. Pam, my brother has not had a recurrence for more than six years.