

**MENTAL HEALTH RECOVERY: WHAT HELPS AND WHAT HINDERS?
A NATIONAL RESEARCH PROJECT FOR THE DEVELOPMENT OF RECOVERY
FACILITATING SYSTEM PERFORMANCE INDICATORS**

RESEARCH TEAM

Steven J. Onken, Ph.D.
Jeanne M. Dumont, Ph.D.
Priscilla Ridgway, A.B.D.
Douglas H. Dornan, M.S.
Ruth O. Ralph, Ph.D.

PARTICIPATING STATES

Arizona
Colorado
Hawaii
New York
Oklahoma
Rhode Island
South Carolina
Texas
Utah
Washington

SPONSORS

Center for Mental Health
Services
Colorado Mental Health
Services
Columbia University Center
for the Study of Social
Work Practice
Human Services Research
Institute
Mental Health
Empowerment Project
Missouri Institute of Mental
Health
Nathan Kline Institute
Center for Study of Issues
in Public Mental Health
National Association of
State Mental Health
Program Directors
New York State Office of
Mental Health
Oklahoma Department of
Mental Health and SAS

**International Recovery Perspectives: Implications – Innovations –
Implementation, November 16-17 2006, University of Toronto, Ontario**

**A Recovery Oriented System:
Summary Tables of What It Is, What It Isn't**

This handout provides tables summarizing the findings of *Phase One Research Report: A National Study of Consumer Perspectives on What Helps and Hinders Recovery*. Please keep in mind that important information, nuances and details get lost in table summaries. These tables need to be viewed hand-in-hand with the text of the report. The report, *Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators: A National Study of Consumer Perspectives on What Helps and Hinders Recovery*, is available online in PDF format at the following website: <<http://www.nasmhpd.org/>>. Click on “publications,” scroll to “National Technical Assistance Center for State Mental Health Planning (NTAC) Publications and Reports,” scroll to and click on “Technical Reports” and the report and appendices are under the 2002 listing. If you have need assistance in getting the online version, contact:

National Technical Assistance Center
66 Canal Center Plaza, Suite 302, Alexandria, VA 22314, USA
Phone: (703) 739-9333; Fax: (703) 548-9517
General inquiries: ntac@nasmhpd.org

During Phase Two, the research team used the Phase One findings to develop two sets of performance indicators, which underwent extensive refinement. The Phase Two Research Report, *Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators: Phase II Technical Report: Development of the Recovery Oriented System Indicators (ROSI) Measures to Advance Mental Health System Transformation*, is available at the same website under the 2006 listing.

In Phase Three, the research team proposes that the ROSI measure (survey and profile) undergo pilot testing, in part to conduct psychometric testing. The research team recommends the development and adoption of guidelines, possibly in the form of a toolkit. The team also recommends that a plan be developed for dissemination of the ROSI, the results of Phase Three pilot testing, and the corresponding toolkit.

The materials herein do not necessarily reflect the positions or policies of any of the project sponsors and state research partners. The materials are based on the cumulative perspectives of the 115 focus group participants as analyzed and interpreted by the five member research team.

THE AMERICAN DREAM – *Because I have had a place where I could live and just be and feel safe, it really accelerated my recovery. (CO 259)*

Basic Material Resources – *I'm stuck. I have to not hardly work at all in order to stay on Medicaid to be able to take care of myself and pay for all those prescriptions and all these doctor bills. (TX 308-311)*

Hinders
Poverty
Unsafe & Unaffordable Housing
Lack of Transportation
Barriers to Benefits & Entitlements
Lack of Communication Services

Helps
Livable Income
Safe & Affordable Housing
Transportation
Information & Advocacy on Services & Benefits/ Insurance Parity
Telephone Service
Resources from Social Networks

CITIZENSHIP – *Often times it's not about pathology, it's just about life. (AZ 739)*

Social Relationships – *Having a friend is a way of feeling comfortable with who I am, having more esteem and respect – esteem and faith in myself and trust to let go and be who I am in a sociable setting. (SC 646)*

Hinders
Inadequate Social Network/ Social Isolation
Emotional Withdraw/ Personal Isolation
Lack of Information for Families and Friends
Controlling Family Members
Lack of Social Skills
Stigma, Prejudice, Labeling, Negative Media Portrayals
Disabling Conditions/ Health Problems
Social Status/ Immigrant Status
Trauma Experiences
Substance Abuse

Helps
Extended Networks/ Kinship Ties/ Friendships/ Affinity Groups (faith communities, tribes)
Personal Ties (at least one person)/Intimate Relationships
Openness to New Information, Strategies, Healing/Advocates within Social Networks
Supportive & Accepting Kin
Communication/ Social Contact (e.g. fun)/ Balancing Solitude and Social Togetherness
Volunteerism
Access to Means of Communication (i.e., phone service, Internet)
Social Choices
Mutual Aid/Interdependence

Meaningful Activities – *The state agency which is supposed to help people with occupational rehab services, told me that because of mental illness, I cannot go to work in the mental health field (which is what I want to do) because I shouldn't be counseling people or I shouldn't be around other people because my illness would prevent me from helping someone else. I'm like, duh, I have a better understanding than anybody else, I think, and I've been working in this field on a volunteer basis as a peer advocate, a mental health advocate. I just want to find a paid position for it. (RI 963-979)*

Hinders
Unemployment/ Role Loss/ Under-Employment/ Limited Range of Jobs
Employment Disincentives in Benefits
Not Respecting Personal Decisions about Job Readiness or Interest
Lack of Training & Education Opportunities
Exploitation of Volunteer Work
Prejudice, Stigma and Discrimination/ Disclosure Fears

Helps
Choice among Meaningful Employment Opportunities
Program and Policy Decision Making
Respect Choices/Readiness for Work
Educational Advancement (e.g., formal, self-directed)
Volunteer Work
Understanding & Respective Employers/ Accommodations
Advocacy Group Participation/ Systems Level Advocacy/ Community Organizing

PERSONHOOD – *Live your life, not your diagnoses. (CO 1309)*

Hope, Sense Of Meaning & Purpose – *Coming to this point where I am saying, “Yeah. I can see a road, and there’s a future.” (TX 732)*

Hinders
Dreams, Goals, Desires Demeaned
Poor Quality Services/ Cutbacks
Pessimistic Staff
Spirituality Discounted or Ignored
Stigma, Prejudice, Discrimination
Sense of Hopelessness/ Negative Beliefs & Attitudes/ Self-Stigma
Disabling Condition Itself
Unfulfilled Basic Needs
Lack of Education on Recovery Resources

Helps
Developing a Sense of Meaning & Purpose/ Having Goals
Meaningful Service Choices
Staff are Hopeful/ Realistic Optimism
Spirituality Acknowledged
Role Models, Friends & Peers
Positive Personal Attitudes/ Hope, Optimism
Reclaiming & Appreciating Personal Strengthens/ Active Coping
Positive Personal Experiences/ Housing & Sense of Home/ Rejuvenation
Gaining Knowledge and Becoming Educated

Self/Whole Person – *Even if you do get worse, this can be compensated by the skills you learn to manage your illness...even if the illness does get worse, this does not mean that your life gets worse. (UT 699)*

Hinders
Negative Beliefs and Attitudes
Not Taking Personal Responsibility
Invalidation and a Lack of Information
A Lack of Discretionary Funds
Disabling Conditions/ Health Problems
Labeling

Helps
Positive Traits and Attitudes
Self Reliance/Personal Resourcefulness/ Dignity of Risk
Information & Education on Disorder
Self Advocacy and Self Determination
Self Care/ Self-Monitoring of Symptoms
Seeing Self as Whole, Complete Person

EMPOWERMENT PROCESS – *It would be nice if a mental health center would say, “These are the services that we should be able to provide to you. We can’t because of funding. But if we could, they might actually be more helpful to your recovery process than what we do have to offer.” Because there’s something that’s really empowering in having at least that knowledge. (OK 856-860)*

Choice – *We’ve got your treatment program all designed. We don’t want your input. Just keep your mouth shut. Sign this thing. This is what you’re going to do. (OK 256 257)*

Hinders
Limited or Lousy Options
Lack of Choices regarding Basic Needs (finances, transportation, housing, socially segregated settings)
Unemployment & Underemployment
Lack of Meaningful Involvement in Treatment Planning/ Lack of Right to Refuse Treatment
Limited Treatment Options
Forced Treatment & Coercion
Family & Professional Control
Lack of Skills in Choice Making
Disabling Condition Itself
Stigma/Discrimination/ Self-Stigma

Helps
Meaningful Options
Expansion of Choices regarding Basic Needs
More Job Choices
Educated on Treatment Options & Best Practices/ Self-Directed Planning/ Advanced Directives
Individualized Services & Treatment Planning/ Expanded Options/ Vouchers
The Freedom of Whether and How to Participate in Programs & Services
Self-Determination
Building Skills and Opportunities for Choice Making
Partner with Others in Recovery

Independence – *Fear keeps people from gaining that independence. (TX 1211) Why should you bother trying if, say, you're going to have another major episode of depression and you are going to be thrown back out with the garbage? Why should you even bother trying again? People certainly have no sympathy in society for you. (TX 1218-1220)*

Hinders
Paternalistic Orientation of the System/ Lack of Respect for Experiential Knowledge
Involuntary & Long-Term Hospitalization
Negative Attitudes & Beliefs (Fear, Lack of Confidence)
Risk & Fear of Losing Benefits/ Clinical Supports/ Safety Net
Stereotyping, Prejudice, Discrimination, Labeling

Helps
Making Own Choices and Decisions/ Increased Consumer Voice in System
Self-Determination/ Advanced Directives
Interdependence & Partnership
Having affordable housing, car, job, etc.
Basic Human and Civil Rights & Freedoms

Peer Support (Referent Power) – *Support from others is very important, especially from others who are in the same predicament that you are. They know what you go through. They've been through it, and they survived, which could help you survive. (TX 1258-61)*

The people that helped me the most in the hospital admitted that yes, they were mental health consumers. They were hired and when they were hired no one knew. (OK 2850-22852)

If we could get funding for [peer education], consumers could be less of a burden on a system that's already overburdened. We could restore some of their dignity, self awareness and self responsibility - personal responsibility that is so absolutely necessary to survive in communal living. (OK 1342-1352)

Hinders
Lack of Funding/ Infighting over Limited Funds
Peer Support Not Available in Many Regions, especially Rural
Limited Participation (e.g., same few people participate)
Limited Leadership Development Opportunities
Formal Service Provider and Staff Control/ Not Controlled by Members
Lack of Independent Peer Support Resources
Professional Mistrust of Peer Support
Lack of Transportation

Helps
Adequate Funding for Peer Support
Wide Availability of Peer Support Resources
Diverse Models of Peer Support (e.g., support groups, warm lines, case managers, etc.)
Role Models & Mentors
Exposure to Self-Help/ Self-Help Philosophy
Support Resources run by Consumers
Consumers employed within Traditional/Formal MH Services
Accessing Other Self-Help Supports & Services (e.g., AA, NA)
Sharing Common Experiences

THE FORMAL SYSTEM – *The system should assume that every person that walks through the door has the potential for recovery rather than the opposite – just automatically assume that recovery is possible. (SC 1286)*

Implicitly or explicitly getting the message that you will be sick for the rest of your life, you'll never get well. You'll have to take meds the rest of your life. Being told you'll never work again. The thing that the system has done to hinder and actually damage me the most is tell me I'll never be well. (AZ 2247)

They use meds as a way to control your behavior – it's like a pharmaceutical handcuff – a medication straightjacket. (SC #1334)

We have a system that's based on helping on an emergency basis only. Does it have to take an emergency before somebody gets help? Does it have to be when somebody pulls the trigger or slices their wrist before somebody finds the help that they need? (TX 1275-80)

Formal Services

Hinders – Organizational Culture & Structure
Culture and Organization that is Pathology-Focused/Illness-Focused/ Dominance of Medical Model
Lack of Change & Innovation
Lack of Holistic Orientation (e.g., neglect spirituality, physical health)
Access Limited to Those in Crisis
System promotes Dependency/ Paternalism & Maternalism
Stigma within the System
Social Segregation
Funding Problems
Lack of Consumer Voice on Personal and System levels

Helps – Organizational Culture & Structure
A Recovery-Oriented System with a Vision of Recovery/ Extending Support beyond Traditional Boundaries/ Consumer-Driven
Encourage Innovation/ De-fund or Transform Ineffective Practice & Programs
Holistic Approach/ Proactive Approach supporting Preventative Measures/Positive Mental Health
Multiple Strategies
Self-Responsibility/ Fostering Growth & Interdependence/ Assistance with Letting go of Dependency on System
Fully Committed to Consumer Voice/ Support Risk Taking/ Freedom to Fail
More Tolerance for Diversity & Unusual Behavior
Adequate Funding and Equitable Distribution of Resources/ Monies Reinvested in Community/ Voucher System
Consumers employed within System at all Levels/ Consumers involved in Decision-making Processes such as Staff Hiring & Firing/ Mandated Consumers Positions on Boards & Committees/ Office of Consumer Affairs/ Ombudsman Program

They bend the people to the program instead of bending the program to the people. (NYC 1152)

It's basically just an ushering in and an ushering out—'Here's some meds, we'll see you in 32 days.'” (CO 2633)

Hinders – Programs & Services
Coercion & Forced Treatment
Treatment/Medication used as a means of Social Control
Debilitating Effects & Experiences of Long-Term Hospitalization
Substandard Services/ Poor Quality Assurance
Limited Access to Services & Supports/ Timeliness, Time limits
Fragmentation of Services, Eligibility Restrictions
Lack of Individualization
Lack of Needed Range of Services, Treatments and Options
Lack of Education for Consumers, Family Members and Community (e.g., illness, self-care, services, etc.)
Inadequate Continuity of Care

Help - Programs & Services
Forced Treatment Avoided
Freedom of Whether & How to Participate in Services & Meds/ Self-Management of Medications
Inpatient Services as Last Resort but Available/ Small Scale/ Alternatives to Hospitalization/ Self-Directed Inpatient Care/ Advanced Directives Respected
Quality Clinical Care/ Consumer-Doctor Partnership/ Up-to-date Treatment Knowledge/ Clean & Modern Program Environments
No Waits/ Flexible
Coordinated Services across Problems, Settings, & Systems/ Effective Case Managers with Low Caseloads & High Pay/ Disengagement or Reductions in Services based on Consumer's Self-Defined Needs
Tailored to Individual/ Wide Range of Choices as to Who Provides, What is Provided & Where Provided
Peer Support Services/ Therapy & Counseling/ Atypical Meds/ Family Services/ Employment Support & Career Development/ Respite Care/ Integrated Dual Diagnosis Services/ Jail Diversion and Community Reintegration Services/ Etc.
Patient Education/ Illness Education/ Information on Meds, Effective Treatments & Services & How to Secure, Rights/ Family Education/ Public Awareness Education (anti-stigma & pro-recovery)
System Navigators/ Extensive Out-reach & Support (multiple languages, 24-7, minority-focused)/ Homeless Outreach/ Safety Net Services
Access to Records/ Can Change Inaccurate Information
Early Intervention & Public Screenings/ Outreach to Churches, Schools, Communities

PARTNERSHIP – *The right staff with patience, time and understanding can help you move along toward recovery. (NYC, 239)*

Formal Service System Staff – *The most important thing is a sense of partnership...I remember the first time (and it was very recently... within the last year), that a psychiatrist actually sat down and talked to me, actually listened to what I had to say. I was feeling a lot of fear and apprehension about some important tasks I had in front of me. He said ‘We’re going to get through this together, you know, this is a team effort.’ News to me. Twenty years of living with [this disorder] no one ever told me that before...This concept that we were in partnership –both of us doing whatever we could to enhance my recovery, understanding that the primary responsibility is with me for my own recovery, not stepping back from that at all – was such a novel thing. (AZ 2373)*

I don’t want to cry all the time and I want to be able to get out of bed but I don’t want to be 950 pounds either. I didn’t have this side effect before I took it. Give me the right to tell you what’s happening with my body and the medication is not working or else the side effect is much worse than not taking the medication. (OK 634-643).

I had a therapist that cared and this was in the public sector. All those people came together one day to an office at a facility and they all sat down with me and talked about how I was going to survive and how they were going to help me survive. We were all going to decide how we were all going to help me get well. Wrap around, where you’re pulling in community, family, faith, work and being holistic. Combining everybody around you who knows about you and everyone being aware of what your symptoms are, how you’re behavior is and then it’s just like a community taking care of you until you’re able to take care of yourself. (Native American describing tribal response, OK 1448-1485)

Hinders
Discontinuity/ Burnout/ Overworked
Low Expectations/Negative Messages
Misunderstanding/Mistrust
Coercion/ Power-Over/ Formal Roles
Paternalism/ No Understanding of Consumer’s Experiences/ Superior/ Disrespectful
Culturally Insensitive/ Devaluing/ Not Much Staff Diversity
Foster Dependency/ Discourage & Undermine Consumer Participation
Inadequate Knowledge & Training (on trauma services, recovery process, effective meds & treatments, etc.)

Helps
Continuity/ One-on-one Relationship/ Availability
Hopeful/ Positive Expectations/ Belief that Recovery is Possible
Understanding, Trustworthy/ Honest/ Open
Partnership & Collaboration/ Treated as Equals/ Provides Practical Support using Multiple Roles
Listened to/ Believed/ Staff are Authentic, Respectful, Supportive, Caring, Responsive, Have Humility
Culturally Sensitive/ Fosters Self-Empowerment
Improved & On-going Training & Education/ Consumers Involved as Trainers

A recovery-based mental health system strives to implement the ideals of a recovery orientation as compared to the focuses of the old paradigm or chronicity orientation, as detailed in the following table, based on the work of Ridgway (1999)¹.

The Chronicity Paradigm	The Emerging Recovery Paradigm
Diagnostic groupings; “Case”; Lumped and labeled as “chronics”/ SPMI/ CMI	Unique identity; Person orientated; Person First Language
Pessimistic Prognosis; “Broken Brain”	Hope and Realistic Optimism
Pathology/ Deficits; Vulnerabilities are Emphasized; Problem-Oriented	Strengths/ Hardiness/ Resilience; Self-Righting Capacities Emphasized
Fragmented Biological/ Psychosocial/ Oppression Models	Integrated Bio-Psycho-Social-Spiritual Holism; Life-context
Professional Assessment of “Best Interests” and Needs/ Paternalism	Self-Definition of Needs and Goals/ Voice/ Consumer-Driven/ Self-determination
Professional Control/ Expert Services	Self-Help/ Experiential Wisdom/ Mutuality/ Self-Care/ Partnering with Professionals
Power Over/ Coercion/ Force/ Compliance	Empowerment/ Choice
Reliance on Formal Supports or “Independence”	Emphasis on Natural Supports; Interdependency
Social Segregation; Formal Program Settings; Deviancy-Amplifying Artificial Settings	Community Integration; “Real Life” Niches; Access & Reasonable Accommodation to Natural Community Resources/ In Vivo Services and Supports
Maintenance/ Stabilization; Risk-Avoidance	Active Growth/ New Skills & Knowledge/ Dignity of Risk
Patient/ Client/ Consumer Role	Normative Roles/ Natural Life Rhythms
Resource Limitations/ Poverty	Asset building/ Opportunities
Helplessness/ Passivity/ Adaptive Dependency	Self-Efficacy/ Self-Sufficiency/ Self-Reliance

¹ Source: Ridgway, P. (1999). *Deepening the Recovery Paradigm: Defining Implications for Practice. A Report of the Recovery Paradigm Project*. Unpublished Manuscript. Lawrence, KS: University of Kansas, School of Social Welfare, Office of Mental Health Research and Training.