WHITE PAPER

ON

RECOVERY AND RESILIENCY

DEVELOPED BY

THE CONSUMER COUNCIL

of the
Indiana Family and Social Services Administration, Division of Mental Health and Addiction
Mental Health Planning Council

November 18, 2006

Transforming the Indiana Mental Health and Addiction Service System to a Recovery Oriented Service System

Introduction

The State of Indiana is beginning the process to transform the existing mental health and addiction services system to one that is an evidence-based, coordinated and efficient service and oversight system which engages consumers and families and promotes access at the earliest possible stage of need to recovery-based services. The Governor of Indiana, in collaboration with the Indiana Family and Social Services Administration, Division of Mental Health and Addiction (DMHA) has recently submitted a proposal to the U.S. Department of Health and Human Services, Substance Abuse and Mental Health Administration (SAMHSA) for funding of the State's transformation planning effort. Within this proposal is a vision that incorporates recovery within a consumer-driven system. (See text box to right for excerpt from the working draft vision and objectives.)

Working Draft

Indiana envisions a future in which . . .

PERSONS with mental illness and/or addiction, or at risk of developing a mental illness or addiction, at the earliest possible stage of need, have access to a care system that provides assessment, treatment, relapse prevention and recovery-based services and support throughout the lifespan.

Objective 1 – CONSUMER-CENTRIC SYSTEM

Indiana is committed to moving beyond the rhetoric of a consumer-driven model to the full reality of a consumer-centric system. At both State and local levels, a series of strategies will be undertaken to ensure that consumers/families are full partners in every aspect of planning for, delivering and evaluating effective care across all systems and age groups.

The DMHA Consumer Council is a group of individuals who have personal experience with the mental health and addiction system in Indiana from the perspective of being recipients of the system's services. From this perspective, the issue of recovery is well-understood. The Council also recognizes that there has been a general lack of acceptance and understanding of recovery for persons with mental illnesses and/or addiction among many service providers, clinical professionals, and the general public.

This **Recovery and Resiliency Position Paper** has been written with the intent of providing information about recovery and resiliency that may be used throughout the system transformation process for public education and policy development. The Consumer Council stands ready as a partner with the State in transforming the mental health and addiction system.

Background

Over the past decade, a national agenda has emerged that addresses the long-term prognosis for persons with major mental illnesses. Partly as a result of the consumer empowerment movement of the 1980s and 1990s and partly as a result of the growing awareness of clinicians and consumers, a recovery construct has been developed. Through research supported by universities, some state mental health agencies, the

Substance Abuse and Mental Health Services Administration (SAMHSA) Center for Mental Health Services (CMHS), and the National Association of State Mental Health Program Directors Research Institute (NRI), recovery in persons with mental illness is now being recognized as a major next goal for persons receiving mental health services.

"Things which matter most must never be at the mercy of things which matter least."
Johann Von Goethe

Historically, serious mental illnesses were believed to be chronic and life-long. Adding to this belief has been the emergence of "scientific" evidence that all mental disorders are biological in nature and, therefore, cannot be prevented. The functional capacity of persons with mental illness was expected to deteriorate over time. The primary goal of services was to slow the deterioration, or to maintain functioning. This bleak prognosis provided the rationale for long-term institutional care and many existing community services. There is substantial and growing evidence that this long held belief does not hold true. Longitudinal studies have demonstrated that recovery from mental illness does occur. The World Health Organization's annual health report, "Mental Health: New Understanding, New Hope" has stated that, with proper treatment, people suffering from mental disorders can lead productive lives and be a vital part of their communities. The report "shows how science and sensibility are combining to break down real and perceived barriers to care and cure in mental health. For there is a new understanding that offers real hope to the mentally ill. Understanding how genetic, biological, social and environmental factors come together to cause mental and brain illness. Understanding how inseparable mental and physical health really are, and how their influence on each other is complex and profound."[1]

Many people diagnosed with serious mental illness appear to recover completely. Even among those who continue to experience symptoms, a recovery of functional capacity is being observed. The growing awareness of this hopeful possibility has recently become a part of the national discussion about mental illness[2].

Studies of resiliency come from both the public health field and the mental health field. Resilience research beginning in the 1970's examined the effect on children of having a parent with a diagnosis of schizophrenia. This research found that only 10% of the children in the study actually developed the illness.[3] The question then is why some children seem to "inherit" the illness while the vast majorities do not. While there may be some interplay between biological and social factors that influence health promotion in children, it is now generally accepted that resilience, or the capacity to bounce back from adverse events, is a key component of an individual's ability to adapt to his/her environment. The use of a strengths based approach to human development and

[1] The World Health Report: 2001. Mental Health: New Understanding, New Hope.
[2] Nullis, Clare (Associated Press Writer) 2001, *WHO Urges Greater Recognition of Mental Health Problems.* Canoe Health Geneva (AP), 04 October 2001.
[3] Garmezy, N. (1991). Resilience in children's adaptation to negative life events and stressed environments. *Pediatrics Annals, 20*, 459–460, 463–466.

functioning has emerged as a way to promote resiliency (or "self-righting tendencies") in individuals, families, and communities.[4]

Increased awareness of the possibility of recovery and resiliency building has implications for policy makers and others associated with the design and delivery of mental health services. The possibility of recovery should increase the demand for services in the community. Community services such as congregate living facilities and day programs can begin to be dismantled, replaced by services that support recovery and build resiliency.

Research

Despite advances in community-based care, mental health treatment and rehabilitation services for consumers with SMI still fall far short of the vision for recovery-oriented services, as expressed in writings of the mental health consumer movement[5] and mission statements for state mental health authorities throughout the US, including Indiana.

Anthony [6] has defined recovery as developing personal meaning and purpose after enduring the effects of a mental illness. In addition, recovery may be both a process for outcomes and an outcome itself. Some common themes of recovery include self-confidence, self-concept above and beyond mental illness, well-being, hope, and optimism.[7] For mental health programs to realize the recovery vision, three things must happen.

> *"To climb steep hills requires a slow pace at first."* Shakespeare

Mental health practices must genuinely foster self-determination and consumer ownership of their treatment and rehabilitation. To attain true recovery from mental illness, consumers must take responsibility for their recovery by becoming active collaborators in the helping relationship and learning specific strategies to manage their

---

[4] U.S. Department of Health and Human Services. (2001). Mental Health: Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.

[5] Dumont, J. and P. Ridgway. *Mental health recovery: What helps and what hinders*. in *Southern Regional Conference on Mental Health Statistics*. 2002. New Orleans, LA.

[6] Anthony, W.A., *Recovery from mental illness: The guiding vision of the mental health service system in the 1990s.* Psychosocial Rehabilitation Journal, 1993. **16**: p. 11-23.

[7] Carpinello, S.E., et al., *The development of the Mental Health Confidence Scale: A measure of self-efficacy in individuals diagnosed with mental disorders.* Psychiatric Rehabilitation Journal, 2000. **23**: p. 236-243.

Corrigan, P.W., et al., *Recovery as a psychological construct.* Community Mental Health Journal, 1999. **35**(3): p. 231-240.

DeMasi, M.E., et al. *Specifying dimensions of recovery*. in *Proceedings: 6th Annual National Conference on State Mental Health Agency Services Research and Program Evaluation*. 1996. Alexandria, VA: National Association of State Mental Health Program Directors (NASMHPD) Research Institute.

Ralph, R.O. and D. Lambert, *Needs Assessment Survey of a Sample of AMHI Consent Decree Class Members*. 1996, Portland, ME: Edmund S. Muskie Institute of Public Affairs, University of Southern Maine.

own illness. Unfortunately, most CMHCs still treat consumers as passive recipients of services. Treatment plans often fail to reflect recovery goals – what the consumers see as important in their own lives. Practitioners continue to presume that consumers need to be protected from stress. Hence, practitioners believe many of their consumers need to live in group homes and other protected settings[8] even though the evidence is quite to the contrary.[9] Similarly, practitioners often assume that consumers are "unmotivated" or not ready for competitive work[10], leading to placement in sheltered workshops or day treatment. Psychiatric medications, another area in which "the doctor knows best," are often given with little regard to helping consumers understand the purpose or the role of these medications within the context of a person's life.[11] Too often, consumers are not given informed choices in medication type or dose or even provided basic competent medication management.[12] The gap is wide between perceptions of unmet needs as seen by consumers and case managers who are all too often paternalistic and directive.[13] The chair of the President's New Freedom Commission on Mental Health has noted "our collective failure to help many people with a mental illness achieve the goals they value".[14]

Mental health practices must be implemented well with high fidelity to the EBPs described in the literature. The national movement toward EBPs has been motivated by the well-known shortcomings of mental health services. These shortcomings reflect the fact that mental health services have been often haphazardly implemented with little attention to well-documented principles of effective practice.[15] *Fidelity* refers to adherence to the underlying principles of a program practice; programs that follow closely the principles of a program practice are said to have high fidelity.[16] Programs that are implemented with high fidelity to evidence-based principles typically achieve better outcomes.[17]

---

[8] Carling, P.J., *Return to community: Building support systems for people with psychiatric disabilities.* 1995, New York: Guilford Publications.

[9] Wong, Y.I. and P.L. Solomon, *Community integration of persons with psychiatric disabilities in supportive independent housing: A conceptual model and methodological considerations.* Mental Health Services Research, 2002. **4**: p. 13-28.

[10] Braitman, A., et al., *Comparison of barriers to employment for unemployed and employed clients in a case management program: An exploratory study.* Psychiatric Rehabilitation Journal, 1995. **19**(1): p. 3-18.

[11] Mann, S.B., *Talking through medication issues: One family's experience.* Schizophrenia Bulletin, 1999. **25**: p. 407-409.

[12] Sheehan, S., *Is there no place on earth for me?* 1982, New York: Vintage Books.

[13] Crane-Ross, D., D. Roth, and B.G. Lauber, *Consumers' and case managers' perceptions of mental health and community support service needs.* Community Mental Health Journal, 2000. **36**: p. 161-178.

[14] Hogan, M.F., *Spending Too Much on Mental Illness in All the Wrong Places.* Psychiatric Services, 2002. **53**(10): p. 1251-1252.

[15] Drake, R.E., et al., *Implementing evidence-based practices in routine mental health service settings.* Psychiatric Services, 2001. **52**: p. 179-182.

[16] Bond, G.R., et al., *Measurement of fidelity in psychiatric rehabilitation.* Mental Health Services Research, 2000. **2**: p. 75-87.

[17] Becker, D.R., et al., *Fidelity of supported employment programs and employment outcomes.* Psychiatric Services, 2001. **52**: p. 834-836.

McHugo, G.J., et al., *Fidelity to assertive community treatment and client outcomes in the New Hampshire dual disorders study.* Psychiatric Services, 1999. **50**(6): p. 818-824.

Consumers must have access to these high quality services. It is well documented that consumers with SMI continue to have problems accessing services meeting even *minimal* standards of care.[18] For consumers with psychiatric disabilities, mental health services are offered within a fragmented system that does not foster rehabilitation or recovery from illness. Despite the good intentions of community programs for treating consumers with severe psychiatric disabilities, a great deal more can be done to foster a true collaboration between consumers and providers to promote recovery and reintegration into society.

Probably the most notable and well-regarded illness self-management training is the Wellness Recovery Action Plan (WRAP)[19] program. WRAP is an integrated package of techniques that are simple, clear, and provide instructions for planning life goals. The WRAP model is an excellent example of a personalized tool to promote recovery for individuals with SMI. The Illness Management and Recovery (IMR)[20] approach contains similar methods, but it is a more formalized curriculum based on evidence-based principles from skills training literature and includes clinical interventions that can be well-integrated into the flow of work in a CMHC. Both WRAP training and IMR are being used within Indiana to promote awareness of recovery.

Characteristics of a Person Who has Recovered from Mental Illness

Dr. Dan Fisher, the Executive Director of the National Empowerment Center and a self-identified consumer with a diagnosis of schizophrenia, is a nationally recognized proponent of recovery. He served on the President's New Freedom Commission for Mental Health and is credited with ensuring that the concept of recovery was embedded

---

McGrew, J.H., et al., *Measuring the fidelity of implementation of a mental health program model.* Journal of Consulting and Clinical Psychology, 1994. **62**: p. 670-678.

Jerrell, J.M. and M.S. Ridgely, *Impact of robustness of program implementation on outcomes of clients in dual diagnosis programs.* Psychiatric Services, 1999. **50**: p. 109-112.

McDonnell, J., et al., *An analysis of the procedural components of supported employment programs associated with employment outcomes.* Journal of Applied Behavior Analysis. Special Issue: Supported employment, 1989. **22**(4): p. 417-428.

Lehman, A.F. and D.M. Steinwachs, *Patterns of usual care for schizophrenia: Initial results from the Schizophrenia Patient Outcomes Research Team (PORT) client survey.* Schizophrenia Bulletin, 1998. **24**: p. 11-20.

[18] Drake, R.E., et al., *Implementing evidence-based practices in routine mental health service settings.* Psychiatric Services, 2001. **52**: p. 179-182.

Lehman, A.F. and D.M. Steinwachs, *Patterns of usual care for schizophrenia: Initial results from the Schizophrenia Patient Outcomes Research Team (PORT) client survey.* Schizophrenia Bulletin, 1998. **24**: p. 11-20.

Lehman, A.F. and D.M. Steinwachs, *Translating research into practice: The Schizophrenia Patient Outcomes Research Team (PORT) treatment recommendations.* Schizophrenia Bulletin, 1998. **24**: p. 1-10.

[19] Copeland, M.E., *Wellness Recovery Action Plan*. 1997, Brattleboro, VT: Peach Press. Chichester. p. 91-109.

[20] Mueser, K.T., et al., *Illness management and recovery for severe mental illness: A review of the research.* Psychiatric Services, 2002. **53**(10): p. 1272-1284.

within the recommendations of that commission. He has published the following seven characteristics that would indicate that a person has recovered from mental illness. [21]

1. Makes their own decisions in collaboration with other supportive people outside the mental health system
2. Has a meaningful and fulfilling network of friends outside the mental health professionals
3. Has achieved a major social role/identity other than consumer (such as student, parent, worker)
4. Medication is one tool among many freely chosen by the individual to assist in their day to day life (used as the chronically normals use medication)
5. Capable of expressing and understanding emotions to such a degree that the person can cope with severe emotional distress without it interrupting their social role and without them being labeled symptoms
6. A Global Assessment of Functioning Scale score of greater than 61: "functioning pretty well, some meaningful interpersonal relationships and 'most untrained people would not consider him sick' "
7. Sense of self is defined by oneself through life experience and interaction with peers

Consumer Council Recommendations

History and Accomplishments:
The Division of Mental Health and Addiction's Consumer Council submitted recommendations for a recovery-oriented mental health system in October 2003. Since that time, some recommendations have been implemented by DMHA and should be acknowledged. The following are the known accomplishments over the past two and one half years:

- The mission statement for DMHA is posted on the website states:

  > To ensure that Indiana citizens have access to appropriate mental health and addiction services that promote individual self-sufficiency.

- The results of the statewide consumer survey have been published for 2002 and 2003 and the report for the 2004 survey is anticipated within the next two months.

[21] Fisher, D. Published on the World Wide Web at http://www.power2u.org/characteristics.htm.

- DMHA has partnered with Key Consumer Organization and provided WRAP training to 232 persons in five community mental health centers, one managed care organization, three other community organizations, and one System of Care.

- Self-Advocacy Training has also been provided to 196 persons in nine community mental health center and three other community organizations through the partnership between DMHA and Key Consumer Organization.

- Olmstead grant funding has been used to provide two leadership academies.

Purpose:
The purpose of these recommendations is to identify the concepts of "Recovery" and "Resiliency" and to promote these concepts as the primary goal of the service system operated by the Indiana Division of Mental Health and Addiction. This action is consistent with the recommendations of the President's New Freedom Commission on Mental Health.

Definition:
Recovery is an intentional and sustained improvement of quality of life, building on personal hopes and strengths.

The Consumer Council believes the Recovery Community is comprised of persons of any age in recovery from a mental illness, serious emotional disturbance or addiction, their family members, significant others, friends, employers, and all people who are dedicated to the health and wellness of persons in Recovery. Whenever appropriate, services should be provided within the person's own community setting, in the least restrictive environment, using the person's natural supports. The service system should assist the person to achieve an improved sense of mastery over his or her condition and to regain a meaningful, constructive sense of membership in the community.

Many Definitions
In the final report of the New Freedom Commission on Mental Health:
Recovery refers to the process in which people are able to live, work, learn, and participate fully in their communities. For some individuals, recovery is the ability to live a fulfilling and productive life despite a disability. For others, recovery implies the reduction or complete remission of symptoms. Science has shown that having hope plays an integral role in an individual's recovery.
Resilience means the personal and community qualities that enable us to rebound from adversity, trauma, tragedy, threats, or other stresses — and to go on with life with a sense of mastery, competence, and hope. We now understand from research that resilience is fostered by a positive childhood and includes positive individual traits, such as optimism, good problem-solving skills, and treatments. Closely knit communities and neighborhoods are also resilient, providing supports for their members.

New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003.

The Division of Mental Health and Addiction has made a strong commitment to Evidence Based Practices. DMHA is to be commended for its role in bringing Integrated Dual Disorders Treatment, Assertive Community Treatment, Supported Employment, Illness Management and Recovery and children's Systems of Care to many communities in Indiana. DMHA should continue to promote mental illness and addiction prevention,

early assessment and intervention, stigma reduction, training centers for evidence based practices and access to appropriate mental health and addiction assessment and treatment for persons within the criminal justice and juvenile justice system.

The Consumer Council believes in access to high quality mental health and addiction treatment. We also believe that there is more to Recovery than just well trained medical staff and pharmaceutical interventions. Major principles at least as essential to the recovery process are hope, education, quality assurance, self-advocacy, personal responsibility, self-determination, support and building resilience.

Hope

> *"If you do not hope, you will not find what is beyond your hopes."* St. Clement of Alexandra
>
> *"Life is a pure flame, and will live by an invisible sun within us."* Sir Thomas Brown

The entire treatment system should support the concept of Recovery, not just in word, but in action. The environment for this system should encourage hope, positive expectations, belief that recovery is possible and emphasis on individual dignity and respect. DMHA should be renamed the Division of Mental Health and Addiction Recovery. Recovery should be the focus of the Division's Mission statement. Mental health professionals should be trained to develop and maintain therapeutic partnerships with consumers and to evolve practice approaches that support recovery. Recovery competencies should be included as part of the professional training for mental health professionals.

The inclusion of cultural competency, recovery competency, bio-psychosocial competency, trauma and abuse competency, spiritual dimension of recovery, non-traditional therapies, consumer participation and other best practices in the design and implementation of professional training programs is also urged. The Recovery Community wants alternative and complementary services to the medical model of service delivery on which most of the Evidence Based Practices are designed.

Education

Consumers and families should have the necessary information and the opportunity to exercise choice over the care decisions that affect them. Programming should be flexible so that services to the Person in Recovery can be individually tailored. The treatment of an individual should be approached from a total recovery perspective. Recovery specialists and care managers should be fully knowledgeable of ALL the resources and treatment options available so that the person in Recovery can choose wisely. Consumers should have access to Recovery Education provided by their peers.

Quality Assurance

Consumer Satisfaction Surveys should be published annually and be available to the Recovery Community to assist in making choices of provider. This information should also be used by the Division as an outcomes measurement in evaluating the quality of services.

The funding that provides institutional care in a state mental hospital should be allowed to fund up to the same amount of community based services for those who can appropriately be served in their community. DMHA should support the Governor's Commission on Home and Community Based Services recommendation that the money follow the individual person to prevent risk of re-institutionalization.

The treatment system should be designed to allow the marketplace to bear on the provision of services. Persons in Recovery should be able to influence service delivery by selecting providers that are responsive to their specific needs. The system should be driven by recovery-based outcomes that persons in Recovery help to develop. Providers should be reimbursed not only for services provided but also when outcomes have been met.

Self-Advocacy

Basic human and civil rights advice and advocacy services should be available for all psychiatric patients. Persons receiving home and community-based services should have access to education on their rights under the Americans with Disabilities Act, and training on self-advocacy, especially regarding reasonable accommodations in housing and employment. A system based on recovery should refrain from the use of seclusion and restraint, develop and implement more humane practices and, focus on limiting people's exposure to coercive measures. There should be broader implementation, and further development of, practice approaches that allow for maximum choice even when individuals are under involuntary treatment.

There should be no wrong doors when entering into the treatment system. Anyone requesting services should not be refused without first being offered a full intake interview and being provided with a written explanation if refused. An individual should be able to enter any appropriate level of care when needed, not just in crisis.

Personal Responsibility and Self-Determination

Persons in Recovery should be able to provide input in all phases of treatment planning, choice of clinician providing the treatment, and evaluation of the services. Mental health professionals should be trained in how to support the consumer's right to make choices, try new things, take risks, and make some mistakes, so long as life is not threatened. Independent living for people with mental illness should be a strong component of mental health policy. There should be an emphasis on creating a variety of housing options that maximize consumer choice and follow the DMHA housing vision statement. There should be specific targeted goals to strengthen and expand supported education and supported employment.

The voice of the Recovery Community should be strengthened through decision-making roles, voting memberships, and actual oversight responsibilities. DMHA should have an ongoing formal feedback process regarding progress on recommendations from advisory groups. Stakeholders who make a commitment of taking personal time from work for task forces deserve a commitment from DMHA to take real action toward systems change. The time and effort of persons in Recovery should be recognized as having a financial value in addition to other benefits in providing the services described in this document. Therefore, applicable travel reimbursement, compensation, education, and other resources should be made available to them in recognition of their commitment for the services provided.

Support

The President's New Freedom Commission on Mental Health states in Recommendation 2.2, "The Commission is convinced of the need to increase opportunities for consumers and family members to share their knowledge, skills, and experiences of recovery."[22] Consumer-run services and consumer-providers can broaden access to peer support (for both adults and youth), engage more individuals in traditional mental health services, and serve as a resource in the recovery of people with a psychiatric diagnosis. Because of their experiences, consumer-providers bring different attitudes, motivations, insights, and behavioral qualities to the treatment encounter. Consequently, consumers should be involved in a variety of appropriate service and support settings. In particular, consumer-operated services for which an evidence base is emerging or has been established should be promoted." There should be investment in the development of a vibrant self-help network. DMHA should increase *individual* consumer self-determination by helping people with mental illness acquire the self-management skills needed to manage their own lives. Peer support services should

[22] New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003.

be integrated into the state hospital system. The Division should begin to provide some funding and support for consumer owned and operated services as adjunct choices within the continuum of community care.

Building Resilience

> *"Our greatest glory is not in never falling but in rising every time we fall."* Confucius

As transformation of the mental health and addiction system in Indiana moves forward, it will be important to understand the role of resilience in prevention and health promotion. As stated in the Surgeon General's Report on Mental Health: "The concepts of risk and protective factors, risk reduction, and enhancement of protective factors (also sometimes referred to as fostering resilience) are central to most empirically based prevention programs." The report goes on to say "the construct of 'resilience' is related to the concept of protective factors, but it focuses more on the ability of a single individual to withstand chronic stress or recover from traumatic life events."[23] DMHA should begin to identify best practices and evidence-based practices for prevention, health promotion, and building resilience. Once those practices are identified, they should become essential and required components of the mental health and addiction system.

Trauma

Finally, a word about trauma and its impact on the mental health and addiction system. "The mental health field lacks sufficient information about dealing with trauma and its effects on different populations. Also, few treatments specifically for adult survivors of childhood abuse have been studied in randomized controlled trials."[24] As consumers/survivors we hold that traumatic events in life are the most significant, identifiable variable in developing mental illness and/or substance use or abuse throughout the life span. For this reason, we plan to begin working on a Position Paper on Trauma that will further define the issues and result in additional recommendations for mental health transformation in Indiana.

---

[23] U.S. Department of Health and Human Services. (1999). Mental Health: A Report of the Surgeon General. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.

[24] New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003.