The Foundation for Excellence in Mental Health Care

Moving Forward Treatment Optimization in the Service of Recovery: Policy Recommendations FINAL DRAFT 04/28/11

Background and Purpose

We propose to fundamentally change the way mental health services are delivered with particular respect to the provision of psychiatric medications. From the evidence of personal experience and a reappraisal of research findings, it is clear that recovery from mental health challenges is probable and should be expected. We assert that mental health conditions no longer result in presumed inevitable or long-term disability. This change in perspective challenges us all (persons with mental health conditions, their families, clinical providers, researchers, payers, regulators, policy makers) to reconsider our beliefs and to create new and effective public policies and practices. We are distressed by the research evidence (or lack of evidence) and lived experiences that point to the ineffectiveness and hazards regarding the use of psychiatric medications.

As our understanding of the recovery process advances, we imagine a future in which psychiatric medications are best utilized in the context of recovery supports, as part of a broader array of clinical, social, spiritual, and environmental supports.

We have come together, a diverse group of concerned and thoughtful stakeholders in the provision of mental health services, to articulate policy recommendations and implementation guidelines that will progressively encourage and facilitate optimized use or non-use of medications combined with other clinical and social services and community supports with the primary goal of promoting recovery. These policies must assure that health system, clinical, educational, and social support approaches are consistent with current and future evidence-based research associated with long-term positive outcomes. The policies must respect and incorporate cultural relevance, a trauma-informed perspective, personal preference, self-determination, person-centered planning, and shared decision making.

Current mental health policies in the United States do not adequately support or incentivize use of psychiatric medications in support of recovery and, in fact, in many cases undermine or prevent actual recovery for many persons with mental health conditions. This reflects a mismatch between the beliefs upon which current

policies are based, the preferences of persons who are the recipients of services, and a comprehensive reassessment of the actual meaning of scientific research into these conditions and treatments.

Definition of Treatment Optimization

Treatment Optimization is an approach to mental health recovery which supports the judicious use or non-use of psychotropic medications based on valid evidence-based research findings and balanced with an array of other effective, recovery-based services and supports. The goal of all of these interventions is to improve and maximize the self-determination, functioning, and quality and meaning of life of people affected by mental health challenges. Treatment optimization includes postponing or avoiding the use of medications in favor of recovery-based psychosocial supports and services, sensitive and collaborative initiation of medication protocols, timely medication tapering or withdrawal protocols, and regular reassessment of recovery status to guide shared decision making to adjust medication treatment.

If the health system and the key policy makers who guide its development and evolution ignore the need for treatment optimization as defined by this policy paper, they increase the risk of continued harm to individuals, families, and the larger community in the form of worsened health outcomes, increased health care costs and waste, and lost contributions to society in the form of productive activity, tax revenues, and the intangible benefits of the social inclusion of persons with mental health conditions into the fabric of our society.

Mental Health Recovery

Treatment optimization is rooted in the expectation that people will recover from mental health conditions through recovery-oriented services and supports, which may include the use of medications but do not rely exclusively or predominantly upon them. We support the definition and components of recovery that were developed through the SAMHSA consensus building process led by mental health consumers, families, providers, advocates, researchers, managed care organizations, state and local public officials, and others.

Recovery is defined as "a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her potential" (See Appendix A for the more detailed definition.).

Policy Recommendations

In support of the definition of treatment optimization (and consistent with the attached SAMHSA mediated recovery definition and peer-generated recommendations documents), the following policy recommendations are intended to improve services and supports necessary to realize treatment optimization.

- 1. <u>Treatment optimization protocols</u> must be developed by qualified psychiatrists and other physicians, in collaboration with consumers and multiple stakeholder groups and with other people who are familiar with the entire range of evidence regarding medications and recovery supports for children, adolescents, adults and older adults with mental health conditions. The studies of greatest interest will be those that incorporate financially unbiased reviews of short-term as well as long-term outcomes.
- 2. Treatment optimization policies must emphasize the principles of selfdetermination, shared decision-making, upholding individual rights, personcentered planning and strengths-based approaches conducive to empowerment and recovery for persons responding to mental health challenges in their lives.
 - a. Information on reducing and discontinuing psychiatric medications:

 Provide information and support through support groups and literature
 about reducing and coming off psychiatric medications to everyone, not
 with the expectation that everyone can or should reduce or come off, but
 with the understanding that each person is different and everyone should
 have the opportunity to discover for themselves what works best for
 them.
 - b. Person/Patient education and consent: Ensure individuals' rights are protected when providing education and informed consent, including decision-making regarding medication use both short term and long term and discontinuation. This includes the ability of persons to seek a second opinion and obtain the latest known information about side-effects and research about medication cessation or continuance. Personal preferences (i.e. to reduce or discontinue medication) should not be contingent upon ongoing receipt of other mental health services, housing or income subsidy.
 - c. Policy development must include consumer/survivor input, and be informed by such documents as the "Medication Optimization, Choice, and Alternatives" statement.

- d. Informed consent language and processes should be reevaluated and revised to reflect a more person-driven, collaborative approach. The full extent of the negative consequences (e.g. long term effects) of medications should be presented with a sufficient and meaningful level of emphasis.
- e. In order to provide a fair opportunity to make fully informed and considered decisions about medications, more time with the psychiatric provider is needed. Assuming that psychiatrists are properly trained, there are several ways to realize this, including increasing the time in standard psychiatric appointments and adopting team-based approaches to the psychiatric appointment using shared decision making strategies.
- f. Services must be tailored to age, cultural and diagnostic population groups. Cultural variation is particularly important with respect to mental health issues. These significant variations of mental health concepts and attitudes across cultures must be understood, respected, and reconciled by all clinicians working with persons who have mental health conditions. Self-determination should be encouraged and practiced at individual and socio-cultural levels, within a framework of human rights.
- 3. <u>Treatment optimization should include wellness activities and interventions that support recovery and may achieve benefits without the use of medications.</u>
 - a. *Supports:* Supports include peer recovery groups (like Dual Diagnosis Anonymous, Recovery Anonymous, etc) and initiatives like warm-lines and consumer-operated drop-in centers and consumer-run organizations that promote peer support services and the development of individual recovery plans.
 - b. Wellness activities: To counter-balance the over dependence on the use of psychotropic medications, it is important to emphasize activities and awareness of the dimensions of wellness including exercise programs, spiritual practices, tobacco cessation, sleep hygiene, abstinence from alcohol and other drugs that destabilize, diet and nutrition, and general health promotion and prevention. Integrated care should emphasize social, psychological, and narrative approaches. Wellness Recovery and Action Plan, Person-Centered Planning, self-direction, and Psychiatric Advance Directives also need to be included as the mechanisms for supporting wellness activities.
 - c. *Service Planning and Interventions:* These supports include evidence-based psychotherapeutic approaches like Open Dialogue and cognitive behavioral therapy, peer support, skills training and other rehabilitative

activities; Supported Housing (with the goal of permanency), Supported Education, Assertive Community Treatment and Supported Employment, symptom management techniques, especially those that assist with decreasing medication dosages, numbers of medications, and duration of taking prescribed psychotropic medications, and where possible, discontinuing psychotropic medications. Other interventions may include wraparound service planning, care coordination, advance directives and end of life planning support.

- 4. Program development and implementation of treatment optimization. Protocols for treatment optimization must be fully integrated into other aspects of program planning, design and implementation with recognition that the most challenging of these will be the assurance of high fidelity implementation. Guidelines for a community based standard of support needs to be established and supported at the federal, state, and local level.
- 5. Alignment of treatment optimization with anticipated health system reforms. Health system reforms are being implemented at the state and federal levels, leading both to increased numbers of persons with health insurance and transformation of the delivery system to provide more access to team-based primary care services and efforts to integrate many aspects of care. With particular reference to the emergence of integrated person-centered primary care homes (and other practice organizations) and efforts to more effectively integrate behavioral health services into those primary care settings, consequently much of the provision of psychiatric medications will be done by primary care and other non-psychiatric prescribing providers. This could lead to a large cohort of persons who continue to be at risk of harms from the premature, inappropriate, or excessive reliance on psychiatric medications to the exclusion of other effective health and social services. It is essential that applicable treatment optimization protocols be proactively developed and implemented in these settings.
- 6. <u>Financial implications.</u> Financial support and alignment of reimbursement incentives should explicitly reinforce treatment optimization in public and private health systems and health plans. Shared risk and shared cost savings supporting recovery outcomes should be considered. States that have medications carved out of their mental health plans should review this arrangement and evaluate the degree to which these arrangements contribute to overuse of psychotropic medications.

- 7. Quality assurance and performance improvement of treatment optimization. Continuous quality improvement models at local, state and federal levels should establish clear standards based on use of treatment optimization protocols; reviews should routinely assess programs for compliance with target population-appropriate protocols and true informed consent; standard reports on quality reviews should always include reference to the degree to which programs and prescribing providers adhere to approved protocols. Protocols should be development independently and without pharmaceutical industry influence. All policies established need to include mechanisms for accountability and enforcement. QA and QI efforts are contingent upon improvements in the process for approval of medications as safe and effective and are dependent on major reforms of the FDA, a subject that is beyond the scope of these recommendations. The appropriate oversight and enforcement of prescribing practices, including certain off-label uses, must be clarified in terms of federal, state, and local authorities. Data collection on prescribing practices should be made transparent and accessible. These data should be utilized to educate prescribing providers regarding their practice patterns.
- 8. Workforce development implications. The implementation of these policies must be supported and incorporated into the process of defining core competencies for various clinical providers. Curricula provided in any relevant undergraduate, graduate, post-graduate, and continuing education programs and credentialing, certification, and professional licensing criteria need to be adapted to incorporate treatment practice guidance as appropriate.
- 9. Training and education for treatment optimization. Professional training programs, including medical schools and psychiatric training programs should develop and teach evidence-based curricula regarding the short, medium, and long-term use of psychotropic medications. Training materials should include the impact and interaction effects of all medications on mind/body/spiritual functioning and supports. These programs should also assure knowledge, skills and attitudes in professionals' education regarding non-pharmacological approaches to controlling and coping with psychiatric symptoms and syndromes. All professional training should provide education on these same issues, adapted for each professional discipline and paraprofessional training level. State licensing boards should require evidence of training in evidence-based approaches to treatment optimization as well as the role of holistic, alternative, and complementary treatment approaches.

- a. Diagnosis Education: Provide accurate and up to date information about what is known and the limits of our knowledge about mental health conditions to ensure informed consent to treatment. Patients and family members should be given relevant and understandable information regarding the known etiologies and physiological mechanisms of mental health conditions in ways that sufficiently balance what we know about biological factors with social, psychological, cultural, and spiritual explanations. Overly simplistic explanations about such conditions being exclusively derived from genetic predisposition, chemical imbalance, and brain disorders should be avoided.
- b. Medication Education: Providers should educate patients and family members regarding what is known and not known about psychotropic medications. Patients should understand that medications may have longer term anatomic and physiological impacts and may increase some risks to mental and physical health, changes that must be balanced against any anticipated benefits.
- c. Peers and advocates should be trained regarding the risks and benefits of medications and this information should be incorporated into shared decision making models, depending on patient preference.

10. Research and evaluation of treatment optimization.

The quality, integrity and interpretation of published studies regarding the benefits and harms of all psychotropic medications need to be reviewed for rigor and accuracy of methodology and research findings. This is especially relevant in the context of recovery, as opposed to mere symptom relief, as a primary outcome. Therefore, the federal government should initiate independent reviews of all existing relevant studies and other datasets, both published and unpublished. The results of these reviews should serve as the foundation for the development of a federally funded strategic initiative of research to investigate how to best utilize psychiatric medications in the recovery context. Federal support should be provided to evaluate and report, on an ongoing basis, what is known about the benefits and hazards of their use. Federal funds should be made available to research centers at universities and medical schools to study and evaluate innovative approaches and comparative effectiveness to medication optimization and alternatives to medication. These studies should be without financial support from pharmaceutical industry to assure the public of unbiased scientific research and data interpretation. Local, state and federal agencies should agree upon a standardized set of practice data and comparative outcome indicators.

11. Use of electronic health records that promote treatment optimization. EHRs should provide support for collection of clinical and program data regarding treatment optimization protocols and practice and the relationship of medication optimization to alternative and complementary treatments and services.

Appendix A The 10 Fundamental Components of Recovery

Self-Direction: Consumers lead, control, exercise choice over, and determine their own path of recovery by optimizing autonomy, independence, and control of resources to achieve a self-determined life. By definition, the recovery process must be self-directed by the individual, who defines his or her own life goals and designs a unique path towards those goals.

Individualized and Person-Centered: There are multiple pathways to recovery based on an individual's unique strengths and resiliencies as well as his or her needs, preferences, experiences (including past trauma), and cultural background in all of its diverse representations. Individuals also identify recovery as being an ongoing journey and an end result as well as an overall paradigm for achieving wellness and optimal mental health.

Empowerment: Consumers have the authority to choose from a range of options and to participate in all decisions, including the allocation of resources, that will affect their lives, and are educated and supported in so doing. They have the ability to join with other consumers to collectively and effectively speak for themselves about their needs, wants, desires, and aspirations. Through empowerment, an individual gains control of his or her own destiny and influences the organizational and societal structures in his or her life.

Holistic: Recovery encompasses an individual's whole life, including mind, body, spirit, and community. Recovery embraces all aspects of life, including housing, employment, education, mental health and healthcare treatment and services, complementary and naturalistic services, addictions treatment, spirituality, creativity, social networks, community participation, and family supports as determined by the person. Families, providers, organizations, systems, communities, and society play crucial roles in creating and maintaining meaningful opportunities for consumer access to these supports.

Non-Linear: Recovery is not a step-by-step process but one based on continual growth, occasional setbacks, and learning from experience. Recovery begins with an initial stage of awareness in which a person recognizes that positive change is possible. This awareness enables the consumer to move on to fully engage in the work of recovery.

Strengths-Based: Recovery focuses on valuing and building on the multiple

capacities, resiliencies, talents, coping abilities, and inherent worth of individuals. By building on these strengths, consumers leave stymied life roles behind and engage in new life roles (e.g., partner, caregiver, friend, student, employee). The process of recovery moves forward through interaction with others in supportive, trust-based relationships.

Peer Support: Mutual support, including the sharing of experiential knowledge and skills and social learning, plays an invaluable role in recovery. Consumers encourage and engage other consumers in recovery and provide each other with a sense of belonging, supportive relationships, valued roles, and community.

Respect: Community, systems, and societal acceptance and appreciation of consumers, including protecting their rights and eliminating discrimination and stigma, are crucial in achieving recovery. Self-acceptance and regaining belief in one's self are particularly vital. Respect ensures the inclusion and full participation of consumers in all aspects of their lives.

Responsibility: Consumers have a personal responsibility for their own self-care and journeys of recovery. Taking steps towards their goals may require great courage. Consumers must strive to understand and give meaning to their experiences and identify coping strategies and healing processes to promote their own wellness.

Hope: Recovery provides the essential and motivating message of a better future: that people can and do overcome the barriers and obstacles that confront them. Hope is internalized; but can be fostered by peers, families, friends, providers, and others. Hope is the catalyst of the recovery process. Mental health recovery not only benefits individuals with mental health disabilities by focusing on their abilities to live, work, learn, and fully participate in our society, but also enriches the texture of American community life. America reaps the benefits of the contributions individuals with mental disabilities can make, ultimately becoming a stronger and healthier Nation.